DOCUMENT RESUME

ED 432 158 FL 025 920

AUTHOR	Tellier-Robinson, Dora
TITLE	The Experiences of Portuguese-Speaking Families with Special-Needs Children as Related by the Mothers: An Ethnographic Interview Study.
PUB DATE	1997-00-00
NOTE	279p.; Ph.D. Dissertation, New York University.
PUB TYPE	Dissertations/Theses - Doctoral Dissertations (041) -- Reports - Research (143)
EDRS PRICE	MF01/PC12 Plus Postage.
DESCRIPTORS	Bilingualism; Elementary Secondary education; Ethnography; Interviews; *Limited English Speaking; Mothers; *Parent Attitudes; *Parent Participation; *Severe Disabilities; *Special Education; Surveys
IDENTIFIERS	*Portuguese Speaking

ABSTRACT

A study examined Portuguese-speaking parents' involvement in and feelings about their special-needs children's education. Ethnographic interviews were conducted, in either English or Portuguese, with nine Portuguese-speaking limited-English-proficient and bilingual parents (eight mothers and one father) of severely challenged children. The report describes the study's methodology and results, and presents nine family profiles, as interpreted from the parents' statements. Themes explored include: learning for the first time about the child's disability; meeting the special needs of the child; relationships with siblings; parent attitudes about their experience; language use in the family; concern for the children's futures; family adjustments; dealing with the medical profession; second language learning; and the meaning of the experience of having a child with special needs. A section is devoted to issues in the children's education, including the nature of schooling in the United States, language and cultural barriers, school placement, educational involvement in the home, parent involvement in school, the differing roles of fathers and mothers, and facilitating involvement. Implications for educational practice are discussed. (Contains 125 references.) (MSE)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 432 158

Sponsoring Committee: Professor Margot Ely, Chairperson
Professor Howard Coron
Professor Miriam R. Eisenstein Ebsworth

THE EXPERIENCES OF PORTUGUESE-SPEAKING FAMILIES WITH SPECIAL-NEEDS CHILDREN AS RELATED BY THE MOTHERS: AN ETHNOGRAPHIC INTERVIEW STUDY

Dora Tellier-Robinson

Program in Bilingual Education
Department of Teaching and Learning

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it
☐ Minor changes have been made to improve reproduction quality
● Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

PERMISSION TO REPRODUCE AND
DISSEMINATE THIS MATERIAL HAS
BEEN GRANTED BY
Dora Tellier-Robinson
TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)
1

Submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in the
School of Education
New York University
1997

FL025920

BEST COPY AVAILABLE

Copyright 1997 Dora Tellier-Robinson

ACKNOWLEDGMENTS

There are many people who have helped make this study a reality. First and foremost, I would like to thank the members of my committee for their help and encouragement. My chairperson, Professor Margot Ely, inspired me with her passion for qualitative research and helped me see this project through to its conclusion. Professor Miriam Eisenstein Ebsworth contributed her unique perspective both as a parent and as an educator to my understanding of the cross-cultural aspects of the work. Professor Howard Coron, with his insightful comments, helped me understand my data in ways I might otherwise not have.

I am also indebted to Professor Dennis Sayers, who awakened my interest in parent involvement and helped me through my proposal and the initial stages of my dissertation. I would like to thank the members of my support group both for their friendship and for the emotional support they gave me. I thank Dr. Margaret Anzul, whose help in editing my dissertation was nothing short of invaluable. In the same vein, I also thank Gerrie Kupper, who went above and beyond the call of duty when she typed this dissertation.

There were others who gave me encouragement and support not only during the conduct of this study, but also from the beginning of my studies at New York University. I would like to

thank Yolanda Cacciolo of The Henry and Lucy Moses Center for Students with Disabilities. The staff of the Bobst Library, especially Tom McNulty, were a great help during this and other research projects. The New Jersey Commission for the Blind and Visually Impaired was a valuable source of support. I also thank my husband Brooks not only for his emotional support, but for his help as my research assistant.

I thank the Portuguese community in the New York/New Jersey metropolitan area, whose members opened themselves to me and made me feel part of their community. Most of all, I would like to thank those families who participated in this research. Without their willingness to share their thoughts and feelings with me, this study would not have been possible.

TABLE OF CONTENTS

ACKNOWLEDGMENTS iii

LIST OF TABLES x

CHAPTER

I INTRODUCTION 1

II REVIEW OF LITERATURE 7

- Parent Involvement in Education 7
  - The Meaning of Parent Involvement 10
  - Parent Involvement in Bilingual Education 12
  - Parent Involvement in Special Education 14
  - Parent Involvement in Bilingual/Special Education 16
- The Importance and Benefits of Parent Involvement 18
- Parents' Attitudes toward Parent Involvement 20
  - Attitudes of Special Groups 20
- Barriers to Parent Involvement 24
- Portuguese-speakers in the New York Metropolitan Area 28

III METHOD 31

- Choice of Method 31
- Stance of the Researcher 32
- Selection of Participants 35
- Protection of Participants 38
- Data Collection 40
  - The Interview Process 40
  - Transcription and Translation 43
  - Maintenance of Log 44
- Data Analysis 45
  - Ongoing Analysis 45
  - Final Analysis 46
- Trustworthiness 47

continued

IV FAMILY PORTRAITS 52

Introducing the Castelo Family 52
  Mrs. Castelo's Story 54
Introducing the Paiva Family 62
  Mrs. Paiva's Story 64
Introducing the Xavier Family 70
  Mr. and Mrs. Xavier's Story 72
Introducing the Duarte Family 78
  Mrs. Duarte's Story 82
Introducing the Carvalho Family 87
  Mrs. Carvalho's Story 90
Introducing the Dias Family 99
  Mrs. Dias's Story 102
Introducing the Gomes Family 109
  Mrs. Gomes's Story 112
Introducing the Davila Family 117
  Mrs. Davila's Story 120
Introducing the Tavares Family 124
  Mrs. Tavares's Story 127

V THE FAMILIES AND THEIR CHILDREN WITH SPECIAL NEEDS: THE BEGINNING TRANSFORMATION 133

Learning for the First Time about Children's Disabilities 134
Children with Special Needs in Their Families 140
  Meeting the "Special" Needs of These Children 141
  Relationships with Siblings 144
  Parents' Attitudes toward Their Experience 148
Language Use in the Families 152
  Language Use of Parents 152
  Language Use of Children 153
Concern for the Children's Futures 156

continued

Thematic Discussion 159
  Theme 1. Having a handicapped child required tremendous adjustments for our family. 159
  Theme 2. I could not make the doctors listen to me when I tried to tell them that there was something wrong with my baby. 163
  Theme 3. My special-needs child requires a lot of extra help and attention. 164
  Theme 4. The learning problems of these children have not prevented them from learning a second language. 166
  Theme 5. This child has been a gift from God. 169

VI THE FAMILIES AND THE CHILDREN'S EDUCATION 172

Portuguese-speaking Parents in an Urban School District 172
  Advantages and Disadvantages of Schooling in the United States 173
  Language and Ethnicity as Barriers for Parents 176
  Parents Coping with the System 179
  Parents' Attitudes toward School Placement 182
Types of Parental Involvement 190
  Educational Involvement in the Home 190
    Therapy 190
    Outings 193
    Homework 194
Parental Involvement in School 196
Differences in Involvement for Parents of Special-Needs Children 198
Attitudes toward Involvement 201
  The Parents on Their Own Involvement 201
  The Parents on the Involvement of Others 203
  What the Educators Said 207
  Differing Roles of Wives and Husbands 209
What Schools Can Do to Facilitate Involvement 210

continued

Thematic Discussion 212
  Theme 1. Involvement in the education of my child with special needs consumes far more time than involvement in the education of my other children. 212
  Theme 2. We have to ask for what we want and fight for our children. Lacking proficiency in English makes it more difficult for us to understand the school system and learn how to procure the services to which our children are entitled. 214
  Theme 3. The schools do a lot to support and involve parents of special-needs children, but we have ideas about how they could do even better. 217

VII SUMMARY, IMPLICATIONS FOR PRACTICE, REFLECTIONS ON METHOD, AND SUGGESTIONS FOR FUTURE RESEARCH 221

Summary 221
Implications for Practice 227
  Metatheme 1. What these children can do is immensely more important than what they cannot do. 228
  Metatheme 2. Parents of such children need to be viewed as very rich resources. 232
Reflections on Method 236
  Gaining Entry 236
  Interviewing 238
  Feelings 241
Suggestions for Future Research 242

BIBLIOGRAPHY 246

APPENDICES 257

A ADVERTISEMENT PLACED IN PORTUGUESE-LANGUAGE NEWSPAPER 257

B ENGLISH TRANSLATION OF ADVERTISEMENT 258

C FLYER IN PORTUGUESE 259

D ENGLISH TRANSLATION OF FLYER 260

continued

E PARENT CONSENT FORM IN PORTUGUESE 261

F ENGLISH TRANSLATION OF CONSENT FORM 262

G POSSIBLE INTERVIEW QUESTIONS (PORTUGUESE) 263

H POSSIBLE INTERVIEW QUESTIONS (ENGLISH) 264

I EXCERPT OF INTERVIEW WITH MRS. DAVILA 265

J ENGLISH TRANSLATION OF INTERVIEW WITH MRS. DAVILA 267

LIST OF TABLES

1 Schedule of interviews with participants 41

2 Language fluency of participants 154

CHAPTER I

INTRODUCTION

Educators have long recognized the importance of the involvement of parents in their children's education. Parental involvement, however, means different things to different people. To some parents and educators, parent involvement means that parents participate in such school activities as parent-teacher conferences and attendance at parents' night. To others, it means being involved with their child at home. To still others, parent involvement means that parents are involved in decision making about what is happening in their child's school. Many researchers agree that for parents to participate effectively in their children's education, there needs to be a partnership between parents and educators (Graves & Gargiulo, 1993; Seeley, 1989; Swick, 1991; Swick, Hobson, & Duff, 1979; Thomas, Correa, & Morsink, 1995; Wolf & Stephens, 1989).

Nieto (1992a) argues that one of the most important types of parent involvement in their children's schooling is the day-to-day supportive participation in their lives: feeding, clothing, seeing that the children get to school on time, talking with them and listening, holding high expectations for them (1992a, pp. 262-265), "and all the unspoken moral support of a sweet look, a smile, and a hug at the right moment" (Nieto, 1992b). She further states that we must consider any way that the parent can be involved as a potential positive tool to use for the child's development in school. Clearing the kitchen table so children can do homework and getting children ready for school are forms of parent involvement. Nieto emphasizes the importance of educators validating all that parents can do rather than approaching issues of parental involvement with prior assumptions about what it is or should be. "We need to ask parents what they want and listen well to the answers." This study was inspired by my wish to follow Nieto's urging--to interview parents of a population of bilingual special education students better to understand their experiences of and attitudes toward their involvement in their children's education.

Perhaps the most comprehensive statement so far made of what parent involvement may mean for parents of limited English proficiency (LEP) was made by Careaga (1988) in a study in which he stated that "for many parents of limited English proficient (LEP) students, however, involvement may be hindered by language barriers, limited schooling, different cultural norms, or a lack of information" (pp. 1-2). In his opinion, the challenge to bilingual education is to set up parent involvement programs that overcome these obstacles. He goes on to say that before these programs can be developed, educators must find out the needs of the community, which is done by finding out about these parents' lives and looking at their interests and concerns. Once these factors are understood, Careaga argues, educators will have taken the first step toward developing meaningful parent involvement programs. It is my hope that the findings of the present study may not only accomplish the goals Careaga advocates, but also may help educators become more aware of the strengths and unique assets the members of these families might contribute.

My interest in parent involvement stems at least in part from my own experience as a LEP student in a special education school. I came to this country from Brazil when I was 14. My mother, who had been divorced from my father for many years, was an employee of an international organization. Because of a problem with my sight, neither public nor private schools would admit me. My mother's lack of familiarity both with the language and with the educational system only compounded her difficulty in finding an appropriate school for me. However, with the help of one of her coworkers, we found a special school out of state for children with sight problems that would accept me. I realize that there was not much parent involvement in that school, and what there was, was very traditional. I went to a boarding school which made parent involvement all the more difficult because our parents lived long distances away. Opportunities for parent involvement included PTA meetings, some parents coming to see their children perform in plays, and some parents taking part in fund-raising activities. My mother was not able to be involved more than she was, not only because of the distance, but also because of her own unfamiliarity with the language and culture. These difficulties often left her overwhelmed and willing to accept anything she was told because "they [the faculty] were the experts."

Although much has been written about the importance of parent involvement, a focus on how parents want to be involved is a fairly recent development. Nieto (1992b) stresses this need, and a few researchers have investigated this issue (Bransford & Chavez, 1988; Chavkin, 1989b; Dauber & Epstein, 1993; Lindle, 1989; Seeley, 1989).

The literature on parent involvement is quite extensive in general education, special education, and bilingual education. There is also a growing body of literature that deals specifically with parent involvement in bilingual/special education settings. Several studies are limited to documenting the attitudes toward parent involvement of various ethnic groups, primarily Hispanic and Asian, and these will be discussed in the following section, but only a few of these studies explore the parents' experiences with involvement or inquire into their wishes. To date, I have not located any studies about the involvement of parents of Portuguese-speaking bilingual/special education students.

In this study, I seek better to understand Portuguese-speaking parents' actual involvement and feelings about their involvement in their children's education. This topic seems worthy of investigation. Exploring the meaning of parent involvement for Portuguese-speaking LEP and bilingual families of special-needs children from their own perspectives may add new information about parent involvement to that already available in the literature. It is my hope that this study will provide educators and researchers with enriched insight into parent involvement in bilingual/special education. It will also allow non-Portuguese-speaking researchers and educators to enter the world of the Portuguese-speaking parents.

The study is designed within the qualitative paradigm, which is particularly appropriate for answering the research question and subquestions. I conducted ethnographic interviews with nine Portuguese-speaking LEP and bilingual families of severely challenged children in their native language or in English, as they preferred. Reports about families were made by eight mothers and one father.

My overall research questions were, "How do Portuguese-speaking parents of special-needs children want to be involved in their children's education?" and "What are their expressed feelings about their involvement?" The following subquestions were addressed initially:

> What is the understanding of these parents regarding their involvement in their children's education?
>
> How are these parents already involved?
>
> What would these parents consider to be an ideal parent involvement situation?
>
> How does their involvement in their special-needs child's education compare with involvement in the education of their nonhandicapped children if they have them?

As the study progressed, the focus widened to include aspects of the following questions:

What is the experience of being the parent of a handicapped child?

How do these participants describe their experiences as bilingual parents of handicapped children in their relations with the school system?

CHAPTER II

REVIEW OF LITERATURE

Parent Involvement in Education

The involvement of parents in their children's education is not a new phenomenon. Parents have played an important role in the education of their children since the beginning of the American educational system (Cremin, 1977). Parents have always been recognized as their children's first and most influential teachers. Before the advent of the educational system as we know it, children's education was seen mainly as the responsibility of the family and the church (Pyszkowski, 1989). In colonial times, children were taught mainly in the home. As schools were established, they were seen as an extension of the home environment. The industrial revolution, with its increased urbanization and immigration, brought about a change in the close relationship between home and school. From the beginnings of the PTA movement in the 1890s to the present, there have been various attempts to bridge the gap between home and school (Moles, 1993). Honig (1979) reports that parent involvement "has played a crucial role in linking the child's home/community world with his formal learning" (p. ix).

The recent increased interest in parent involvement is the direct result of a series of federal laws and reports. Rosado and Aaron (1991) state that as the result of the National Commission on Excellence in Education report, A Nation at Risk (1983):

> Government and school officials initiated massive efforts to motivate parents to get involved in the educational process. . . . Most of these programs were geared toward middle-class educated parents. (p. 24)

Barquet (1993) points to the trends in parent involvement toward accommodation of the needs of both majority and minority populations:

> As the students in our classrooms become more diverse . . . teachers and administrators are increasingly eager to find more effective ways to work with students and their parents in order to combat the low achievement and high dropout rates that plague our schools today. (p. 6)

Head Start, begun in 1965, recognized the role of parents in their children's development and included parents in schools as aides and tutors (Epstein, 1984). Comer (1991), when reporting on his pioneering efforts at the Yale Child Study Center to involve inner-city minority parents in their children's education, stated:

> Parental participation in all schools, particularly low-income schools, is extremely important in this modern age . . . when family and community support is not as strong as it used to be. (p. 188)

Title VII of the Elementary and Secondary Education Act of 1965, which dealt with bilingual education, clearly mandated parent involvement on a national scale by calling for the establishment of advisory councils, the majority of whose members must be parents or other representatives of LEP children (Crespo & Louque, 1984). Henderson (1987) states unequivocally that "children from low-income and minority families have the most to gain when schools involve parents" (p. 10). Bermúdez (1993), however, points to the fact that despite the legal mandate for LEP parents to participate in their children's education, these parents remain to a large extent disengaged from the educational process. Several researchers point out that the way to ensure a successful parent-involvement program is to strengthen the support systems within the child's community, especially the home and family (Bermúdez & Marguez, 1996; Chavkin, 1993; Nissani, 1990; Scott-Jones, 1993).

The Education of All Handicapped Children Act of 1975 (P.L. 94-142)--now referred to as IDEA, Individuals With Disabilities Education Act of 1990 (P.L. 101-476)--mandated parent-teacher cooperation in setting educational and developmental goals (Epstein, 1984). Turnbull and Turnbull (1982) say:

> Rather than mandating that all parents be equal participants with the school personnel to make decisions jointly, "public policy should tolerate a range of parent-involvement choices and options, matched to the needs and interests of the parents. (Federal Register, 1981, p. 120)

Simpson (1990) agrees with the need to go beyond mandated parent involvement and points to the need for trust and rapport between parents and professionals as a prerequisite for a successful parent-involvement program. Baca and Cervantes (1989), as a result of their work with LEP minority parents, emphasize the need to take into account the parents' language, culture, and attitudes toward handicaps when developing and implementing a parent-involvement program.

The Meaning of Parent Involvement

Leading researchers of parent involvement agree that the phrase refers to a broad range of activities, both in and out of school, in which parents participate to help their children succeed in school. They also agree that because there are so many types and levels of involvement, there is no hard-and-fast definition of just what constitutes parent involvement (Epstein, 1986; Henderson, Marburger, & Ooms, 1986; Moles, 1993; Nieto, 1992a; Scott-Jones, 1988; Simich-Dudgeon, 1993; Swick, 1991; Swick, Hobson, & Duff, 1979). The different activities that constitute parent involvement are best described by Joyce Epstein (1986, 1987, 1988) in her five types of parent involvement. These types of involvement were developed as the result of

> . . . a formal survey of first-, third-, and fifth-grade school teachers in most of the public schools in the state of Maryland in the spring of 1980. This survey is the first phase of a larger study that will give teachers information about the efforts of these parent-involvement strategies on the teachers who use them and on the parents and students who are affected by them. (Becker & Epstein, 1982, p. 86)

This expanded view of parent involvement has been mentioned in several articles in the literature (Council of Chief State School Officers, 1991; Moles, 1993; Twillie, Petry, Kenney, & Payne, 1991; Violand-Sanchez, Sutton, & Ware, 1991). The five types are:

Parenting. This includes feeding, clothing, and providing a safe environment for the child. These are all the day-to-day activities associated with rearing children and teaching them the skills that make them members of a family and a culture. All of these activities become more challenging for parents of children with special needs and for nonnative speakers of English.

Communication. This involves the school keeping the parents informed about what is going on with their children's education, in as simple and jargon-free a manner as possible. Schools need to develop strategies to make sure that the information sent home is not only just reaching home, but is also read and understood. Successful communication is especially challenging between speakers of different languages, as will be discussed further on.

Volunteering. This includes the more traditional types of parent involvement such as parents working as classroom and cafeteria aides.

Learning at home. This involves parents helping children with their homework. Schools can encourage parents to help their children with their homework by providing information to the parents, scheduling school projects on weekends so that parents have time to help. Based on her research in the Maryland public schools, Epstein states that this is the area in which parents most want help from their schools (Brandt, 1989). Eglesias (1994) stresses the need for teachers to inform parents about what their children are learning in school and if necessary teach them how to reinforce this at home. He emphasizes that this process of informing parents must go beyond "merely enumerating the particular skills that the child must learn . . . the parent and the teacher must remain in constant and frequent contact" (p. 26).

Representing other parents. This includes parents being involved in PTA/PTO, community boards, advisory councils, etc.

Even though these five types of parent involvement have different goals, they are not mutually exclusive. They very often blend and overlap. As Epstein, during a conversation with Brandt (1989) points out, "the five types of parent involvement occur in different places, require different materials and processes, and lead to different outcomes" (p. 24). Helping children with their homework can be seen as an extension of more general parenting skills. By providing the parents information about the school, educators can encourage parent involvement in all these different areas.

Parent Involvement in Bilingual Education

Title VII of the Elementary and Secondary Education Act of 1965 mandates parent involvement in bilingual education. Schools that receive Title VII funding are required by law to establish parent advisory councils (PACs) to help the schools plan, operate, and evaluate Title VII programs. This legal requirement is by no means a guarantee of effective parental participation in bilingual programs. School officials are often suspicious of the PACs and have established them only because they are required to do so by law (Ohio State Department of Education, 1984). Nieto

(1985) sees the whole question of parent involvement as one of power relationships. She states clearly:

> Those who enjoy a certain degree of power in the goings-on of the school are not likely to give it up; those who are powerless do not usually care to become involved in projects not leading to changes in power relationships. (pp. 180-181)

To bridge the gap between schools and LEP parents and involve these parents in their children's education, Epstein (1986) states that there are three requirements on the part of schools:

> . . . awareness of English proficiency among parents of the students; commitment to solving the problems of all parents, including developing comprehensive programs of all types of parent involvement; and action to extend opportunities for all or most parents to become involved in one or more types of parent involvement, especially in ways that will assist the daily success of their own children in school. (p. 14)

Nieto (1985) sees the need for schools to change the way they look at parent involvement. She believes that in bilingual education parent-involvement programs have actually discouraged parent participation. She suggests that the goal of parent involvement in bilingual education should be to educate and empower parents. Before parents can become involved, they must learn that they have the power to change the status quo. Ultimately, the schools must be "run by or with the community rather than for it" (p. 187). She goes on to say that schools will know that they are on the right track when, among other things, ". . . we begin to really listen to parents and when this listening is transferred into action that benefits children" (p. 187).

Harry (1992c) sees a similar power relationship between African-American parents and special-education professionals. Hanson (1992), addressing those in the helping professions who work with families of children in early intervention programs, argues that each child and each family unit should be viewed individually rather than through "categorical approaches to understanding ethnicity" (p. 17). She goes on to say that "knowledge and understanding, sensitivity, and respect for these cultural differences can significantly enhance the effectiveness of service providers in the helping professions" (p. 17). Ideally, the empowerment of parents in bilingual contexts is most effectively based on the attitudes of mutual understanding, sensitivity, and respect that are bridges to overcoming cultural and linguistic barriers.

Parent Involvement in Special Education

Before the passage of P.L. 94-142, the Education of All Handicapped Children Act of 1975 (now referred to as IDEA), parent/professional relationships were best described as difficult and often contradictory. At different times, parents have been seen as responsible for their children's handicaps, a hindrance to their children's education, or a source of expertise about their children (Gargiulo & Graves, 1991; Turnbull & Turnbull, 1990). Parents, in their turn, have viewed professionals with feelings of awe, suspicion, fear, or a mixture of the three (Gargiulo & Graves, 1991). However, with the passage of P.L. 94-142 (IDEA), parent involvement has become an important issue in special education. This law gives parents rights and responsibilities that they never had before. The law requires that parents be involved in all phases of the child's assessment, evaluation, and placement. They should be able to consent to or withhold their consent from the evaluation and placement of the child. They must have access to their child's school records and help plan and evaluate the child's Individual Educational Program (IEP) (Hardman, Drew, Egan, & Wolf, 1993; Hogan, 1990; Simpson, 1990; Turnbull & Turnbull, 1990).

Although parent involvement is mandated by law and widely accepted as beneficial, programs are often implemented in such a way that nothing actually changes (Alexander, 1982; Kroth, 1985; Shea & Bauer, 1985). Teachers are still seen as experts, and parents remain receivers of knowledge (Michael, Arnold, Magliocca & Miller, 1992). Kroth (1985) points to the existence of communication gaps and differences in value systems between parents and professionals. To bridge the gaps between parents and professionals, he suggests that professionals must not only understand their own value systems and that of the parents, but must also help the parents to understand their own value systems.

For parent-involvement programs to be effective, parents and professionals must work together in an atmosphere of mutual trust and respect. Professionals need to see parents as an asset rather than a hindrance (Swick, 1991; Thomas, Correa, & Morsink, 1995; Turnbull & Turnbull, 1990). Alexander (1982) points out that based on sheer numbers, parents are a resource that must be exploited:

> Since there probably will never be enough professionals to serve the needs of children, either educationally or therapeutically, it makes sense to involve parents actively in the education of their own children. But the involvement will have to be what parents are ready for and be geared to parents' backgrounds. (p. 300)

Parent Involvement in Bilingual/Special Education

In many ways the history of bilingual and minority parents in special education parallels that of majority parents in special education. They have been blamed for their children's handicaps, or they have been largely ignored. The main difference is that their minority/LEP status was in and of itself often seen by educators as a disability (Baca & Cervantes, 1989; Gelb, 1982; Harry, 1992b; Marion, 1981). Merely being a member of a minority culture and speaking a foreign language were seen by teachers as handicaps to be eradicated as soon as possible. The rise of special education in the early years of this century can be seen as a means of coping with the large numbers of non-English-speaking children who entered the school system, many of whom were put in classes with the "feebleminded" (Gelb, 1982).

According to Marion (1981), the 1960s brought about a change in attitudes toward minority languages and cultures. They were no longer seen as disadvantages but were assigned "inherent positive values" (p. 215). P.L. 94-142 (IDEA) extends to the LEP parents of children in special education the same rights and responsibilities as it does to majority-language parents (Baca &

Cervantes, 1989; Marion, 1981). Marion (1981) stated that P.L. 94-142 (IDEA) assumes that professionals will treat minority parents as coequals and not as adversaries. This law also mandates that schools act in good faith with minority parents to implement the act's provisions.

Even though P.L. 94-142 (IDEA) mandates parent participation, there is evidence in the literature showing that participation by LEP parents of exceptional children is minimal. This lack of participation is due to several factors. These include lack of knowledge by parents of their rights under P.L. 94-142 (IDEA). Above all, LEP parents of exceptional children need information. It is the responsibility of professionals to explain to these parents, in terms they can understand, the rights and responsibilities they have under this law (Baca & Cervantes, 1989; Carrasquillo, 1990). Another factor in the lack of participation by these parents is a conflict between the attitudes and perceptions of professionals and of the parents about a wide range of topics dealing with special education. Professionals often perceive parental deference to them and preoccupation with such basic needs as feeding and clothing the child as apathy or lack of interest in education (Baca & Cervantes, 1989; Correa, 1989; Harry, 1992a, 1992b; Kroth, 1985; Simpson, 1990).

In order to deal successfully with LEP parents of exceptional children, professionals need to help these parents understand not only the educational system, but also American culture in general (Correa, 1989). Professionals must become aware of their own cultural biases. They must learn to appreciate the value in diverse cultures and become attuned to those cultural differences that may affect their dealings with LEP parents. Professionals need to be aware of pertinent legislation and must modify their own style to deal with members of particular minorities (Allen, 1994; Simpson, 1990). Correa (1989) states:

> School professionals must take the first step toward developing collaborative relationships with culturally diverse families. . . . Once that step has been taken, it is almost certain that families will move toward becoming equal partners in the educational process. (p. 144)

The Importance and Benefits of Parent Involvement

The importance and benefits of parent involvement have been well documented in the literature. There is conclusive evidence that when parents are involved in their children's education, children do better in school (Chavkin, 1993; Chavkin & Williams, 1988; Comer, 1986; Dornbusch & Ritter, 1988; Henderson, 1987; State of New Jersey Department of Education, 1984). Parents play a crucial role in their children's development. They are their children's first teachers, and they have great influence in their children's educational success. Becher (1984), in her review of the literature on parental involvement in education, points out that there are several ways that parents' behavior influences their children's achievement. Parents with children who have good scores on achievement tests have high expectations for them. They also spend more time with them, use more complex language, and consider themselves as their children's teachers.

Comer (1991), when reporting on the results of his study with inner-city children, states that in order to learn, children need emotional support from parents, teachers, and other adults who are influential in their lives. He goes on to say that there is a positive correlation between parent involvement and a positive learning climate. Gordon (1978), in his review of the literature on the effects of parent involvement, found that parent involvement needs to be comprehensive and long-lasting in order to be effective not just on children's achievement, but also on the quality of schools.

Parent involvement is particularly important in bilingual education. A strong relationship between the school and the minority culture and acceptance of that culture by educators has been shown to help the academic performance of minority children (State of New Jersey Department of Education, 1984). Violand-Sanchez, Sutton, and Ware (1991) address the possible relationship between parent involvement in their children's education and the academic progress that language-minority students make and their attitudes toward learning. Cummins (1991) states:

> When educators involve minority parents as partners in their children's education, parents appear to develop a sense of efficacy that communicates itself to children, with positive academic consequences. (p. 379)

Careaga (1988) points out that successful parent-involvement programs are beneficial to all concerned. Teachers have their lessons reinforced at home. Administrators are able to develop more effective strategies. Children see a lessening of potential conflict between the home and the school cultures, and the LEP parents often find participation as a good introduction to American culture.

Turnbull and Turnbull (1990) and Shea and Bauer (1985) list the multiple benefits of increased parent-professional cooperation in special education. These benefits accrue to children, parents, teachers, and schools. Parents and teachers gain increased respect for one another. They come to view each other as allies rather than antagonists. The schools gain the parents as important advocates for their plans and programs. Best of all, "most parents and educators recognize that services for exceptional children improve with parent-teacher cooperation" (Shea & Bauer, 1985, p. 72). Thomas, Correa, and Morsink (1995) state that in this age of increased cultural diversity not only between parents and professionals but also among professionals themselves, the need for collaboration among all parties concerned in a child's education has never been greater.

Parents' Attitudes toward Parent Involvement

Attitudes of Special Groups

Any discussion of attitudes toward parent involvement is necessarily complicated because of the different groups involved. The attitudes of parents, educators, and of the children themselves in the upper grades must all be examined in order to understand why some parents are involved in their children's education and others are not. Researchers agree that independent of their socioeconomic, linguistic, racial, minority, or immigrant status, all parents are interested in their children's education (Cardenas, 1993; Chavkin & Williams, 1993; Dauber & Epstein, 1993; Moles, 1993). This view contradicts a widely held belief among teachers that many parents, especially minorities, immigrants, and those of low socioeconomic status (SES), are not interested in participating in their children's education (Chavkin, 1989a; Ritter, Mont-Reynaud, & Dornbusch, 1993).

There are common factors that link the attitudes of parents of all groups concerning participation in their children's education. Just as there is evidence in the literature showing that parents are interested in their children's education, there is also evidence that parents are concerned with being actively involved in their children's education (Chavkin, 1989a; Rich, 1988; Williams, 1991). Parental desire to be involved is often not immediately evident. For various social and cultural reasons, some groups are less likely than others to express their concerns and desires. Yao (1993) points out that many Asians think that asking the teacher too many questions is disrespectful because it challenges the teacher's authority. Gelb (1982) sees a similar pattern among Asian parents of special-needs children who often assume a passive role in IEP conferences. Both researchers point out that this behavior is particularly characteristic of newly arrived Asian-American immigrants. Gelb (1982) also notes that although Chinese-Americans are solicitous in caring for their disabled children, mental and emotional disorders are often stigmatized. Turnbull and Turnbull (1990) point out that even though it is often difficult for Asians to seek counseling for their emotionally disturbed children, because of a belief that such problems should be handled within the family, they may be much more willing to accept medical or therapeutic services that are seen as technical. These three authors say that it is important to give these parents information about the American educational system.

Moles (1993) and Ritter, Mont-Reynaud, and Dornbusch (1993) make reference to the similarities between Asians and Hispanics in their deferential attitudes toward school authorities. Baca and Cervantes (1989) note that among some Hispanics respect for the professional status of teachers is so great, and the transfer of authority to the school as the child's primary caretakers is so complete, that these parents consider that it is not their prerogative to interfere with or question decisions made by educators. Hispanics also have a strong sense of family, which can make it difficult for them to accept severe handicaps because they are seen as a negative reflection on the family (Harry, 1992b). Gelb (1982) points out that it may be particularly difficult for Mexican-Americans to accept that the oldest male child has a disability. He also notes that because of a history of discrimination, many Mexican-Americans are suspicious of special education, and the child's need for services must be proved to them. This suspicion of special education, and indeed of the school system in general, has been seen in the literature as characteristic of African-Americans (Harry, 1992b). Stein (1983), on the other hand, reports that black parents of learning-handicapped (LH) children are more likely than Hispanics to participate in the process of assessing the child and developing his or her IEP. This finding was despite their overrepresentation in special education, which Harry (1992b) reports is a major reason for their distrust, especially when it comes to mild disabilities.

Despite their negative experiences with the school system, African-Americans are more likely than Asians or Hispanics to have contact with the schools (Ritter, Mont-Reynaud, & Dornbusch, 1993). Bauch (1988) suggests that black parents may be better disposed to parent involvement because they see the need for education as a means for advancement more acutely than other groups. Most low SES parents have a history of negative contact with the school system (Davies, 1993; Lueder, 1989). Chavkin (1989b) states clearly that "although some barriers are found more often with minority families, obstacles to effective parent involvement occur regardless of cultural or minority status" (p. 281). Shriver and Kramer (1993) point out that parents with higher incomes were in fact more likely to feel that educators did not value their input in their child's evaluation process. The negative experiences that many minority and low SES parents have had with the educational process have created mistrust of schools on the part of parents and a gap between home and school (Comer, 1991).

Barriers to Parent Involvement

The barriers to meaningful home and school collaboration fall into three main categories: attitudinal, breakdown in communication, and logistical. As mentioned above, many teachers still believe that parents do not care about their children's education, and many parents are distrustful of the educational process. When it comes to parent involvement in high school, the students themselves are a major barrier because they do not want their parents to be involved (Williams, 1991). Educators have in the past questioned the value of parent involvement (Gargiulo & Graves, 1991; Shea & Bauer, 1985). Even when educators accept the value of parent involvement, they often try to restrict it to traditional areas, such as audience, home tutors, or school-program supporters, and keep parents out of policy-making roles (Williams, 1991). Dornbusch and Ritter (1988) report that although high-school teachers would like more contact with the parents of children who are having problems, they have little contact with the parents of average students (the bulk of the student body) and do not desire increased contact with these parents. Simpson (1990) reports that in special-education programs, teachers have difficulty empathizing with parents who are different from themselves. Cardenas (1993) states that

Hispanic parents do not participate because schools do not adapt parent-involvement programs to meet their needs. Comer (1991) points out that most staff members have never been trained in parent involvement. Emphasizing the need for schools to take the initiative in fostering involvement, Clark (1988) says that if schools do not provide parents with information and strategies for helping their children learn, parents are likely to perceive themselves as inadequate as educators of their children.

Some parent attitudes are also barriers to parent involvement. Gargiulo and Graves (1991) note that in special education "parents, on occasion, can be demanding, uncooperative, overly dependent, defensive, and hostile" (p. 117). Shriver, Kramer, and Garnett (1993) point out that "individual parents are not equally ready, skilled, or interested in being involved in their children's education" (p. 271). Leitch and Tangri (1988) note that some parents have unrealistic desires and expectations of what the schools can accomplish. These researchers see these attitudes as linked to lack of information on the part of both parents and teachers about community services and resources. The same authors also note that parents frequently mention lack of time as a barrier to their greater participation. Yet their findings indicate a higher level of participation among employed parents. Paradoxically, even seemingly positive attitudes can be barriers to parent involvement. Yao (1993) points to many Asians' great respect for and confidence in teachers, which often lead to the belief that merely communicating with teachers is "checking up" and therefore disrespectful.

Another barrier to parent involvement is a breakdown in communication between parents and educators. As the findings of researchers in interlanguage pragmatics have pointed out, misunderstandings can arise between persons of different cultures over role expectations and through language limitations (see, for example, Thomas, 1983). Such misunderstandings can seriously impede fruitful interactions between home and school and have a negative influence on parent involvement.

Crago (1994) points out that many educators fail to recognize the strong relationship between language and culture. She goes on to state that this has led to patterns of communication being "almost exclusively unidirectional" (pp. 11-12). By this she means that nonmainstream children and their parents are expected to change their pattern of communication to accommodate educators and clinicians rather than those professionals trying to deal with their clients in a "culturally congruent manner" (pp. 11-12).

Lynch (1992) points to the complexities of establishing "effective interpersonal interactions" and achieving "cross-cultural competence" (p. 44) between persons of different cultural backgrounds even when they both speak the same language. The various studies in interlanguage pragmatics presented by Kasper and Blum-Kulka (1993) provide some indications of types of speech acts that are influenced by cultural customs. Among these are apologies (Bergman & Kasper, 1993), complaints (Olshtain & Weinbach, 1993), and expressions of gratitude (Eisenstein & Bodman, 1993). Rintell (1989) underscores the difficulty for nonnatives of understanding and conveying emotion in a second language. Cheng (1994) emphasizes the need for professionals "to identify 'foregound information,' or that which is needed to understand the intended meaning of a speaker" (p. 188). Although she is addressing professionals working with Asian students, her suggestions about the need for understanding the "conversational rules that underlie the interactions of LEP students" (p. 188) certainly apply to interactions with their parents as well.

Logistical problems form the third set of barriers to parent/school collaboration. These problems affect not only parents but also teachers, many of whom are themselves working parents. Moles (1993) notes that union contracts and custodians' hours make it difficult to schedule conferences in the evenings at hours that are convenient to parents. He adds, however, that such scheduling can be a real burden to teachers who have their own family responsibilities. Beyond scheduling, several authors (Cassidy, 1988; Chavkin, 1989b; Turnbull & Turnbull, 1990) list child care and transportation as possible barriers to parent participation. In early childhood education, Honig (1979) talks about the project secretary's telephone voice and bus drivers' behavior toward children's families as areas that might be barriers to parent involvement.

Dauber and Epstein (1993) state that when parents perceive that schools have strong programs to encourage parent involvement, they are more involved. These authors believe that all schools, even those in the inner city, can develop programs to involve parents and help them become knowledgeable partners in the education of their children. Rich (1988) suggests that involving families in children's education "is doable, but not without an infrastructure, which, up to now, has been severely lacking, even in affluent settings" (p. 90).

Portuguese-speakers in the New York Metropolitan Area

According to the 1990 census, Portuguese is the tenth most widely spoken minority language in the United States. There are more native speakers of Portuguese in the United States than of Japanese or Arabic, for example (Waggoner, 1992). Between 1980 and 1990, the number of people in the United States born in countries where European languages other than Spanish are spoken declined by 13.8%. During the same period, the number of people in this country born in Portugal and Brazil (countries where Portuguese is spoken) increased by 15.9%. This increase is due largely to greater numbers of Brazilians entering this country (Waggoner, 1993).

The current wave of Portuguese immigration dates from 1966, the year of the passage of the Immigration and Nationality Act of 1965. Most of these immigrants go to areas of older (pre-1922) Portuguese settlement: California, the New York metropolitan area, and southeastern New England. In cities such as New Bedford and Fall River, Massachusetts, the majority of the population is Portuguese (Simões, 1991). The trend is now for most of these immigrants to go to the Northeast rather than to California. About 25% to 35% of the immigrants go to the New York/New Jersey metropolitan area (Pap, 1981).

According to Pap, the Portuguese immigrants have traditionally come from isolated rural areas, and that trend has continued. He also points out that among these earlier immigrants, education was viewed as a hindrance to a child's going out and earning a living. However, the new wave of immigrants (post-1966) are better educated than those in the past (Pap, 1981). Conversations with Portuguese-American educators have revealed that there is still an emphasis among immigrants on children going out to work. The main reason for Portuguese immigration to the United States has been and continues to be economic, combined with a desire to join family members already here (Pap, 1981). Simões (1991) writes, "Most of us who are children of immigrants know that the reason our parents left their land was to have a better life" (p. 101).

Increasing immigration from Brazil should ensure that the number of Portuguese speakers in the United States will continue to increase. Margolis (1994) points out:

> Even the most conservative estimates of the Brazilian population in the various regions of the Northeast and in the United States as a whole suggest an undercount ranging from 33% to over 80%. (p. 256)

She suggests that there may be as many as 350,000 to 400,000 Brazilians in the country. The 1990 census counted 94,023 Brazilians in the United States.

CHAPTER III

METHOD

Choice of Method

Qualitative methods are particularly appropriate for this study because they encourage the expression of the participants' point of view. One of the principal qualitative methods is the ethnographic interview.

> Interviews are at the heart of doing ethnography because they seek the words of the people we are studying, the richer the better, so that we can understand their situations with increasing clarity. (Ely et al., 1991, p. 58)

To paraphrase the words of Seidman (1991), the purpose of in-depth interviews is to understand the experience of other people and the meanings they make of their experiences. It is my hope that by following the procedures outlined below I have been able to collect a body of data that, by means of analysis, will help educators better understand the perceptions and needs of these parents with regard to their involvement in their children's education.

Qualitative researchers seek to give meaning to the participants' experiences within the context of their "real" lives. Sherman and Webb (1988, p. 7) state:

> Qualitative implies direct concern with experience as it is "lived" or "felt" or "undergone." Qualitative research,

> then, has the aim of understanding experience as nearly as possible as the participants feel it or live it.

According to Bogdan and Biklen (1992):

> The qualitative researcher demands that the world be approached with the assumption that nothing is trivial, that everything has the potential of being a clue that might unlock a more comprehensive understanding of what is being studied. (pp. 30-31)

Stance of the Researcher

Any ethnographic researcher must be concerned with the general topic often termed "the stance of the researcher." Therefore, I would like to describe in this section the past experiences that I brought to this study. I am a native speaker of Portuguese who was a special-needs child in an American special-education school. Given my background, my interest in this topic may seem obvious, could almost be taken for granted. In fact, my path to this topic is much more convoluted than it first appears.

When I started school in the United States at the age of 14, it was in a school for the blind and visually impaired in an English-only environment. I was quite literally left to manage as best I could on my own. I now see that I was not the only one who was expected to sink or swim. My mother was also. We were both confronted with a system that made few concessions to our very special needs. It was done out of ignorance and not in malice. Teachers and administrators wanted to help, but in most cases they did not seem to know how. They did not know much about our language or culture and, therefore, had great difficulty responding to our needs. In those days (the mid-60s), parents of special-needs children had very little voice. LEP parents of special-needs children had no voice at all.

Almost all the students from my school who went on to college went into special education. It seemed to me that they never really grew up and left the sheltered environment of special education. As a teacher, I never had or wanted to have much to do with either special education or bilingual education. I wanted to get as far away as I could from what is often considered the stigma of special education. I taught preschool to upper-middle-class monolingual English-speaking children. Sometimes, however, I had the opportunity to teach and/or advise LEP students and their parents, usually Portuguese or Spanish speaking. Some of these children, because of language difficulties, had been classified as special-needs children. Despite my earnest efforts to the contrary, my interest in special education and a desire to help Portuguese-speaking children and their parents kept coming to the fore. Very often I was the only one who could communicate with these people and mediate between them and the school system. As a child, I had not had any support of the kind I tried as a teacher to give others because I had been the only "foreigner" in the school. I came to realize that it was extremely difficult for Portuguese-speaking special-needs children to get the services to which they were entitled.

As I have matured, I have come to see how important it is to give voice to these parents. They are the experts on their own situation and can provide valuable insights into their child's personality, habits, and interests. I hope that this study will be a first step in that direction. I hope to make the concerns of Portuguese-speaking parents of special-needs children known to the wider audience of educators and professionals.

My personal experiences raise the question of open-mindedness and how I have worked toward it. I hope that my years away from bilingual and special education have served me well by allowing me to step back and view the data with a detached eye of an outsider. Because I am close to this topic and of the same cultural background, I was an insider to the participants. Our common cultural background and my personal experience with special education encouraged the parents to confide feelings and experiences they might not have divulged to others. Further steps I took to achieve a more effective stance are detailed in the later section on trustworthiness.

My assumptions about parent involvement have changed. When I started teaching, I did not want parents in the classroom. I believed that their presence would be disruptive not just to me but to the children. I also assumed that parents would rather leave the education of their children up to the experts. Later, however, when I taught at a cooperative school, I saw that parents both wanted to participate in their children's education and could do so successfully. I still assumed that the phenomenon was limited to highly motivated parents in the upper-middle socioeconomic strata. I also assumed that LEP parents of special-needs children were not interested in participating in their children's education because the needs of their special-needs children were so overwhelming that they would leave the education of their children up to the experts. Later still, as part of a course, I conducted some interviews with Portuguese-speaking LEP parents of children with special needs on what they thought about parent involvement. To my surprise, I found that these parents were just as interested in being involved in their children's education as the upper-middle-class parents. They told me that no one had asked before either about parent involvement or about their feelings about having special-needs children. It was then that I decided to give them voice.

Only by openly discussing the assumptions brought by the researcher to the research project can the reader accurately interpret the results of that research. It is in that spirit that I have detailed key assumptions that I brought to my study.

Selection of Participants

Seidman (1991) suggests that the participants in ethnographic interview studies experience similar social structures and conditions. The study was designed with a focus on limited-English-proficient or bilingual, Portuguese-speaking families of children enrolled in special-education programs. I decided to concentrate on a nearby urban area with a large Portuguese community. This is a long-established community where Portuguese speakers are represented in the school system as students, teachers, and administrators. The neighborhood has the largest community of continental Portuguese in the United States. This community has been represented in the school system for at least two generations. It also has a growing number of Brazilians. I first gained entry into this community while doing a pilot study for courses in the doctoral program. During the course of that research, I made important contacts at the local board of education in special education and bilingual education, both Portuguese and Spanish. The participants were selected with the help of a Portuguese-speaking teacher. I also placed advertisements in Portuguese-language newspapers and posted flyers on church and school bulletin boards. An example of an advertisement is shown in Appendix A. Appendix B provides an English translation. Appendix C shows an example of the flyer. An English translation is provided in Appendix D. There were no responses to these notices, however. All the participants came through individual contact. To protect their anonymity, all names of persons and places have been given pseudonyms.

Following a lead given to me by a Portuguese-speaking educator, I was in touch with Mr. Elias, a Portuguese-speaking official at the local board of education working with bilingual programs. He gave me the names of special-education teachers and administrators who he thought could help me. He also gave me the name of a man I have called Mr. Xavier, a Portuguese friend with a special-needs child. I immediately telephoned Mr. Xavier and explained my research project to him. He expressed an interest in participating, and we made arrangements to meet in order to discuss the matter. During the course of that first telephone conversation, Mr. Xavier gave me the name of an administrator at the school his son Jorge had previously attended who was also the parent of a special-needs child. I was in touch with Mrs. Godwin who, although very interested in the research, could not be one of the participants because she was not Portuguese. Mrs. Godwin told me that she worked with a Portuguese-speaking mother of special-needs children. Mrs. Castelo, who worked at a desk next to Mrs. Godwin's, picked up the telephone to talk to me. I explained my research to her, and she immediately agreed to be a participant. We made arrangements to meet at the school to discuss her participation.

I then asked Mrs. Castelo if she knew a Mr. Del Valle, one of the teachers Mr. Elias had mentioned who might be helpful to me. He happened to be in the office just as Mrs. Castelo and I were speaking, and she put him on the telephone. I explained my research to Mr. Del Valle, who agreed to participate in the meeting that I had set up with Mrs. Castelo. I met with them the following week. Mr. Del Valle and I discussed strategies for tracking participants before he left. Mrs. Castelo and I discussed the research again and went over the consent form, which she signed. We made an appointment to meet the following week for the first interview.

Up to a few years ago, a participant pool would have consisted almost exclusively of Portuguese people. Recent immigration from Brazil, however, often to areas with established Portuguese communities, adds Brazilians to the pool of potential participants. Economic problems have led Brazilians to seek opportunities outside their country almost for the first time in their history. From the mid-1980s, a larger number of Brazilians than ever before has come to the United States. Some have brought children with them, and these children have already entered the school system. These Brazilians add an element of ethnic and racial diversity to this community which is not found in the more homogeneous Portuguese population. I had hoped to be able to include Brazilians in this study but was, in fact, only able to locate one family that agreed to participate.

Protection of Participants

Because ethnographic researchers usually deal with intimate and delicate topics, it is important for them to protect the anonymity of the participants. Spradley (1979) asserts that safeguarding the rights and sensitivities of the participants is the primary responsibility of an ethnographic researcher. I took the following steps to protect the interests of the participants.

I conducted a preliminary meeting with each participant prior to data collection. During this meeting, I explained my purpose and obtained the signature for the written consent form. I also used this preliminary meeting as a window to the concerns of the participants. This information enabled me to prepare to conduct the formal interviews by giving me a tentative idea of the direction these interviews might take. My experiences in the preliminary interviews helped me to refine my phrasing of the interview questions.

I requested from all participants their permission to tape the interviews. All but two gave this permission. I also offered to destroy all tapes on completion of the study, but those participants who had given me permission to tape said that would not be necessary. All tapes of the interviews were kept in a secure place. The interviews were translated by me and transcribed by me or by a professional transcriber. Not only were the participants given pseudonyms, but also any details about their occupations, children's handicaps, education, or other details that might identify them were altered or disguised. I explained these steps to the participants as early as possible in the interview process. The participants were also provided with a consent form, in Portuguese, explaining the proposed study and their participation in it. (See Appendix E for example of Consent Form. Appendix F provides an English translation of the Consent Form.)

Data Collection

Although the primary method of data collection for this study was the ethnographic interview, in qualitative research observation is inextricably linked to the interview process (Ely et al., 1991). The interviews were conducted in the Portuguese-speaking community, usually in the participants' homes. This approach provided opportunities for me to observe the interactions of parents and children in their natural settings and added a background of rich description to the interview data.

One interview each with two potential participants who, in fact, did not participate in this present study was held as a preliminary field study. These interviews took the form of informal conversations in the participants' homes and in their native language. In the course of these conversations, questions emerged as the participants talked about themselves and their experiences, and the interview guide for this study was developed from that field trial. See Appendix G for an outline of tentative interview questions in Portuguese and Appendix H for the translation.

The Interview Process

The entire interview process took a period of 16 weeks. The interviews were conducted according to the schedule in Table 1. Nine familes were interviewed three times each.

Table 1

Schedule of Interviews with Participants

	Week															
Participant	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Castelo	1	2	3													
Paiva		1	2	3												
Xavier					1	2		3								
Duarte							1	2	3							
Dias										1	2,3					
Carvalho										1	2	3				
Gomes													1	2,3		
Davila													1,2	3		
Tavares														1		2,3

BEST COPY AVAILABLE

All of the participant families included father and mother. In all but one of the families there were siblings. I conducted informal interviews with both parents, the special-needs child, and whatever siblings were present in all families. In all but one family, formal interviews were held with the mother only. In one case, the Xaviers, both parents participated in the formal interviews.

Interviews for seven of the nine families included were held in their homes, for the other two in locations they specified as more convenient. I conducted these interviews in either Portuguese or English at the participants' preference. I tape recorded the interviews with the permission of the participants, except in the case of two who requested that they not be taped.

I followed Seidman's (1991) method of in-depth phenomenological interviews, the goal of which is "to have the participant reconstruct his or her experience within the topic under study" (p. 9). A series of at least three interviews, each lasting at least 90 minutes, was planned. Ethnographic interviews are by nature unstructured and conversational. Seidman suggests, however, that the interviewer have in mind a focus for each interview, and I followed his suggestions to the extent that I could do so conversationally.

As Seidman (1991) writes, "At the heart of interviewing research is an interest in other individual's stories because they are of worth" (p. 3). In ethnographic in-depth interview research, the participants are not just subjects of study. They are active participants with the interviewer in a process of discovery. This is not to say that the interview process happens by itself. Patton (1987) describes interviewing as "an art and science requiring skills, sensitivity, concentration, interpersonal understanding, insight, mental acuity and discipline" (p. 108).

In order to establish rapport, I opened each interview conversationally with comments about the home or whatever other topic presented itself. I then led the conversation to the backgrounds of the parents, their own education, and how their parents were involved in it. The talk then moved on easily to the present, their children, and especially the special-needs child. Often the participants wanted to know about my own life and experiences that were related to theirs.

Once started on the topic of their lives with the special-needs children, the interviews all flowed very freely. My main task then became to direct the conversation back at some point to issues about the children's education and their involvement in it, and I attempted to redirect it, when necessary, by singling out a relevant topic already mentioned and probing for additional information.

Transcription and Translation

As anticipated, most of the interviews were conducted in Portuguese. I first transcribed them in Portuguese and then translated them into English. Even though I am fluent in both languages, I employed the services of a colleague who is a professional translator further to ensure that the participants' own words were faithfully rendered in the English translation. (See Appendix I for a segment of an interview in Portuguese with accompanying translation.) I used the traditional log format for these transcriptions, in which the data will be presented single space with at least an extra inch of margin to facilitate writing notes and with each line on the page numbered for easy reference. These interview transcripts formed the backbone of the data for the proposed study.

Maintenance of Log

The interview transcripts were not, however, the only data. I kept a log which recorded observational notes as well as my feelings and perceptions about the interviews and about the participants. Included in the observational notes were details of the participants and their surroundings. I also recorded conversations that took place before and after the tape-recorded interviews, as well as any exchanges among family members that might have interrupted the flow of the formal interview. I also recorded hunches and observations that helped me make decisions about ongoing data analysis and refined my interview questions. As Ely et al. (1991) state:

> The log is the place where each qualitative researcher faces the self as instrument through a personal dialogue about moments of victory and disheartenment, hunches,

> feelings, insights, biases, and ongoing ideas about method. (p. 69)

For the purpose of analysis, the log itself is an integral component of the data. Maintaining a log is thus an essential part of the process of qualitative research.

Data Analysis

Ongoing Analysis

In qualitative research, "it is difficult to separate the process of gathering and analyzing data" (Seidman, 1991, p. 86). Most qualitative researchers emphasize the importance of ongoing analysis during the process of data collection. Tesch (1990) stated that the two processes of collection and analysis occur concurrently and inform one another. In this study, data analysis was ongoing and paralleled data collection. Ely and her colleagues (1991) emphasize the need for ongoing analysis and outline steps for establishing preliminary categories for analysis. These steps include intimate acquaintance with the data, the noting of meaning units in the margins of the log, and the gathering together of meaning units into categories. I had assumed that the analysis would be guided by the initial research problem and questions and that the data would yield categories related to the meaning of parent involvement in the education of the special-needs children. However, I attempted to remain open, flexible, and willing to shift perspectives about the same pieces of information in search of the participants' understanding of their experiences. Because parent involvement had such a broad meaning for these participants, categories were also established that concerned aspects of the families' experiences as members with their special-needs children and as members of the Portuguese-speaking community.

Another aspect of ongoing analysis is the recording by the researcher of his or her own feelings, preliminary hunches, doubts, and questions. This is usually done in the form of analytic memos.

> Analytic memos can be thought of as conversations with oneself about what has occurred in the research process, what has been learned, the insights this provides, and the leads these suggest for future action. These memos are written about entries in the log, and they themselves become part of the log. They may be expansions of the spontaneous "observer comments" that are often woven into the entries. (Ely et al., 1991, p. 80)

Final Analysis

The steps in final analysis included a complete re-reading of the transcripts and other log material and a review of the audiotapes to catch inflections, emphasis, and moments of particular emotions that may not be reflected in written form. Approaches for the analysis of qualitative data derive from the data themselves.

All data from the interviews and my reflections were analyzed inductively. Lincoln and Guba (1985) describe inductive analysis as moving from

> . . . specific raw units of information to subsuming categories of information, in order to define local working hypotheses or questions which can be followed up. (p. 203)

The preliminary list of categories was compiled following the steps outlined by Ely (1991, pp. 87-89). These were then reviewed, refined, and combined as necessary. Categories include:

> Attitudes toward family having a special-needs child in the family.
>
> Parent's relations with school personnel.
>
> Opportunities for involvement in child's school.

After the categories were established, I studied them for thematic connections within and among them.

> A theme can be defined as a statement of meaning that (1) runs through all or most of the pertinent data, or (2) one in the minority that carries heavy emotional or factual impact. (Ely et al., 1991, p. 150)

Following the steps outlined by Ely (pp. 150-152), a thematic analysis was undertaken of the final categories presented in Chapters V and VI. Thematic statements were constructed that expressed the understandings and feelings of the participants. The final discussion of findings was organized according to these thematic statements.

Trustworthiness

Within the qualitative research paradigm, trustworthiness is the principal standard for assessing credibility of the study. Ely and her colleagues (1991) call trustworthiness "the 'quality control' of qualitative research." They go on to explain that

> . . . the quest is to make the research project credible, produce results that can be trusted, and establish findings

> that are, to use Lincoln and Guba's phrase, "worth paying attention to." (p. 156)

They thus put fairness at the heart of the whole question of trustworthiness. Participants are to be treated fairly both in the way research is conducted and information is gathered and in the way that the product of the research is presented. The results of the research should accurately represent the experience of the people being studied.

To be fair is to try not to let our prejudices and assumptions intrude too much into our research and especially into our findings. We have to keep in mind, however, that no one can be completely objective, and we all carry our cultural baggage with us. When doing this type of research, we need to be aware of our prejudices in order to keep them from intruding. In general, it is a good idea for the researcher not to become too closely identified with the participants. This was no easy task in this study because I was striving, among other things, for an intimate knowledge of the participants' world, and it was very similar to that from which I came. By the same token, the researcher should not be antagonistic to the participants, as such an attitude could color the researcher's judgment. In two cases, I found it difficult to establish an initial rapport with the participants because they seemed somewhat suspicious of me as a stranger and reluctant to talk about their special-needs children. I was, however, able to overcome this, and they became valuable resources in the study.

In order to establish trustworthiness, I used the following techniques as suggested by Lincoln and Guba (1985):

Prolonged engagement. A period of 16 weeks was devoted to intensive interviews with the participants. Three interviews were conducted with each participant, and these lasted from 90 minutes to over two hours. (See Table 1 for interview schedule.) All interviews were conducted in their homes or elsewhere in the community. This permitted me to immerse myself in the world of the participants.

Participant checking. Participant checking is the sharing of findings with the participants. This strategy is done better to ensure that the researcher's interpretations express meanings as understood by the people who are being studied. I did check selected findings with each of the participants to be sure I had interpreted their meanings correctly and adequately and also because I feel it is their right to be informed of them. In most cases, they agreed that I had captured their meanings. If I had not, we rephrased the passage until it met with their agreement.

Peer checking. Peer checking is a process of sharing the data with peers in order to get their comments and interpretive insights. During much of the research process, I was a member of a support group of other doctoral candidates. I submitted many sections of this document for their critique. A professional transcriber/translator served as another source for peer checking. Finally, I discussed all findings with another professional colleague who read the entire document and with whom I discussed my analyses of data in detail.

Negative and discrepant case analysis. Analysis for these cases is a search for differences and discrepancies in the findings that may help shape and redefine them. I accomplished this by ongoing recursive analysis of the categories, themes, or other interpretive devices derived from the interview transcripts. Ely and her colleagues (1991, p. 161) describe negative case analysis as an active process of confirmation during which qualitative researchers are willing to restructure their interpretations of findings when the analysis of data so indicates. A discrepant case, or findings relating to only one or a minority of participants, may call for a change in interpretation or the statement of minority themes. I did conduct such an analysis, but did not uncover negative or discrepant cases. One participant, Mr. Xavier, did express what seemed to me ambivalent information about certain topics, and these are mentioned in the presentation of findings, where relevant.

I believe that the research methods chosen for this study were well designed to establish trustworthiness. In the research narrative, I put the participants' responses in context and allowed them to be interpreted in the light of responses of all the other participants. I think that the importance of this process lies in its ability to give voice to the participants. This process enables the participants to give their own meaning to their experience rather than having that meaning imposed solely from the outside.

CHAPTER IV

FAMILY PORTRAITS

In order to give as complete a picture of the participants and their lives as possible, I shall briefly introduce each participant and his or her family. These introductions are followed by portraits written in the first person. They have been constructed from the interview transcripts, most of which were translated from the Portuguese as described in the previous chapter. The often-rambling interview material has been edited and restructured to provide a logical and chronological shape to the accounts, but the participants' own ways of expressing themselves have been adhered to as much as possible. I will follow each portrait with my impressions of the participants' families, their special-needs children, and how I perceive the family situation as a whole. Beginning with Mrs. Castelo, portraits of the participants are presented in this chapter in the order in which I interviewed them.

Introducing the Castelo Family

Mrs. Castelo is an attractive woman in her early 30s who has been married for about 14 years and has four children: Nadia, a girl eleven years old; Benito and Nei, who are seven-year-old twin boys; and a younger daughter, Sandra, who is six years old. Benito and Nei are both in special education. Benito is classified autistic and has almost no speech. He attends a special school for autistic children. Nei, who had also been classified autistic, is currently classified emotionally disturbed. Mrs. Castelo told me that Nei's classification was changed when he started to talk. He attends a regular elementary school where he is given extra help in a resource room with a special-education teacher.

At Mrs. Castelo's request, we conducted the interviews in English. I interviewed her in the school where she works. She chose this location because she felt that we would have fewer distractions than at her home. When the interviews were over, she invited me to her house to meet her children. Mrs. Castelo lives in a spacious two-storey house that has recently been renovated. Unlike many families in the neighborhood, the Castelos occupy the whole house.

The first of her children I met was Sandra, the youngest. When I came in, Sandra was seated at a round dining-room table doing her homework. When we were introduced, she seemed very friendly and eager to show me what she was doing. Nadia, the oldest child, was still at school, and I was not able to meet her.

When I met Nei and Benito, I noticed that they are of normal size for seven-year-olds. Nei is slim, and Benito is both tall and a little chubby. Nei acted very shy and would not talk to me or look at me when I introduced myself to him. Benito seemed to be withdrawn and self-involved. I had the impression that Mrs. Castelo is glad that Benito looks like other children and that from his appearance it is not obvious that he has a disability.

I found Mrs. Castelo to be very open when discussing how she felt about having a child with autism. I also found her to be very well informed about autism. She said she was active in a support group for parents at Benito's school and an organization for parents of children with autism. She emphasized that her experiences in these two organizations made her realize that it was helpful to talk to other parents in similar situations. Mrs. Castelo also appeared to find talking to me about her children and their handicaps to be a liberating experience. She was very eager to show me how she works with Benito to encourage him to speak. Although Mrs. Castelo admitted that it is difficult having two children in special education, she appeared to be coping very well.

Mrs. Castelo's Story

I have been in the United States since 1972. My parents brought us here when I was eleven years old and my sister was about ten for us to better our lives. My father came first, got everything ready, and then we came. I don't remember much about Portugal, but I like to go there for a vacation. We were there five years ago and the boys weren't talking yet, but my youngest daughter was saying a few words. My oldest daughter spoke

Portuguese, but now she is losing it. The best thing for me to do, if I could, would be to go home to Portugal every year.

When I came here, I started in the fifth grade. I finished high school and then went to secretarial school for one year. I always had plans to go into education, but I fell in love and got married when I was 19. My husband is Portuguese, and he came here in about 1968 or 1969. I wanted to go to college, but in my second year of high school, I met him. I wanted to go out with him, but my mother didn't allow it until I was 18. He's the first guy I met, and now he is my husband. He is the only one I want. My parents are strict . . . not overly strict, but strict. I like that. I'm trying to be the same way with my kids.

My husband and my father work together for a big construction company. We have four children, and they were all born here. We have an eleven-year-old girl. We waited three years for her. After almost four years, the twins were born. The following year we had another little daughter. The little one was a surprise--we weren't really expecting her. The last few years have been hard. The boys were just months old when she was conceived. They were only about a year or a year and two months old when she was born. I used to carry the two of them around when she was still in me. It was hard. I thought that she would be born with problems, but she is fine.

When the boys were born, their physical development seemed fine to me. Then my little girl started to babble and talk, and that sort of drew my attention because she was only 13 months old and started to sound words. My two sons, who were already two and one half years old, weren't saying anything. The pediatrician kept telling me to give the boys more time, but eventually she referred me to a child development center, which in turn referred me to a hospital. I went there and was told that they were both autistic. It hit me like a time bomb. It was hard. That word, that word autistic, I didn't even know it existed. From then on, I had to read a lot about it and what it meant. At first I didn't even want to talk about it, but then I became a member of an organization for parents who have autistic children.

I started looking for special-education programs for Benito and Nei. They were already two and one half years old. The doctors told me it was good that I started early because early intervention is better. I went to the board of education, and the boys were tested and retested. They were both put in a special preschool handicapped program in a regular school.

The first year they attended the afternoon session. It was sort of like kindergarten. The second year my son Nei started talking, and then he was placed in the morning session, which was more advanced. Benito stayed on in the afternoon session. When they finished the preschool handicapped program, Nei stayed at the same school and he did kindergarten and first grade. Today he is in second grade and he is doing well.

The other son, Benito, completed his preschool handicapped program, but he was placed at another school. He really started the autism program there because the school is for trainable and multiple-handicapped kids, and that year he was placed in it along with five other kids. During the first year, I saw very little improvement. During the second year, I didn't see any improvement at all. I went to the child-study team because I did not think that this was the right placement for him. This school is a good school for other classifications, but not for autism. He needs what is called an extended school year because otherwise he will regress. Now he's at a school for autistic children. The director has a son who is autistic, and a lot of the professionals at that school either know people who have autistic children or have worked with autistic children for a long time.

In the school Benito previously attended, they didn't do anything with signing. This new school thinks that combining the signing with trying to use the words helps him more. They want him to sign, but at the same time try to say the word, for example, "cookies." He will say "oo" because he can't get that "c" sound. They are trying to bring sounds to him. He's trying hard. Before, I didn't have any videotapes at home of him at school, but now I do. We have a videotape with him in situations, like with food, table situations. My other children try to use signing with words so they can talk to him. Benito is starting to say more words. When they are home and they are finished with their homework, they look for Benito so they can play with him.

I can't do everything that they do at school. It's hard for me to do it. They told me to work with him during the week or sometimes on the weekend. I also met with the case manager. She told me that he is very receptive, but he's not very expressive. She knows that he is a bright little boy. He's got things in him, but he doesn't know how to express them.

Nei is still at the same school, but he was reclassified from autistic to emotionally disturbed because he started to talk. However, he is not yet normal; he has tendencies toward autism. Nei is very shy. If you try to talk to him, he will walk like a robot. If something is taken away from him, he throws a tantrum. That's why I think he's classified as emotionally disturbed, which they call ED. They had to classify him as something. They have other classifications, such as NI, which means neurologically impaired. But for him, since he is in a regular school, they thought that ED is better. He has a resource room and receives more attention because that's what he needs. I think I am happy with the school. Nei is doing second-grade reading and second-grade everything.

Autistic children need to have a routine. If you take Benito out of his routines, he gets upset. Sometimes I have taken him out of them. The teacher said that she is trying to bring him out of his world. When he comes home, I try to ask him things and talk to him a little bit, but he won't answer. Then I have to take care of the other ones. I do give him his two or three minutes. The other ones need more time from me to help them with their homework, so Benito goes upstairs to watch television, and he is happy.

The only way I can work with him is when he is around in the kitchen or something. I'll have him say things. My husband just wants to talk more with Benito; he doesn't like the signing, and it upsets him. My husband wants to talk to Benito as to any of the other children. To my husband, Benito should be just like the others. We just treat him the same. That's what we're supposed to do. I think that although he has a disability, we have to treat him as if he did not. It was hard at the beginning, but he understands more now. We didn't used to get any response from him. He would just stand there like a statue. Now he understands more. We try to treat him just the same, but in some ways he's not the same. It is very hard.

When the children were all in school, I wanted a part-time job so I could be at home with my children. I got a job as a secretary in the school Benito was attending. I just work in the office and the cafeteria with the kids. When I started in this school, I just used to cry at first when I saw Benito across the cafeteria. The first three days I really became upset. Benito is at another school now. I think that taking him out of here was the best thing. I didn't think that it was a good idea to work here and have him here, too. My feelings were always hurt.

I think that I became a better parent by working at the school that Benito attended.

I'm a school secretary three hours a day. Then at 1:00 p.m. I go home or do shopping. After that I just go home and wait for the kids. The girls are close to me, and at 3:00 p.m. they're home. Sometimes I like to go to get them. Usually, I have my oldest one looking out for the little one. I get the girls, and they start on their homework. Then about 3:30 p.m. my Nei comes in, and he has homework, too. Then Benito comes in about 4:00 p.m. It is a long day for him. He's on the bus at 7:00 a.m., and he comes home at 4:00. He is the first one to be picked up and the last one to be dropped off. He has no homework. I try to communicate with him. If he goes to the refrigerator, I try to communicate with him by asking him what he wants. I have to try to talk to him because he will get lazy and not want to speak.

I try to have dinner about 7:00 p.m. Everybody eats together. My husband is not always home at dinnertime. In the winter, he is definitely; but in the summer, he's not. So we can't wait for him. I just keep his dinner in a covered dish, and he eats it when he gets home. Then the children go upstairs to take a bath. I try to work with Benito in the bathtub. He does fine in the bathtub. He loves water. I ask him for the shampoo and the soap and everything.

At first they wanted to give me some time to myself. They would send somebody home to stay with Benito while I would go shopping. I didn't want that. I want him exposed to society. I want him to know how to be out there. He goes to places and he is great. All I have to do, really, is make sure he doesn't get lost.

With Nei, well, he still has some autism things in him. He gets upset and he throws tantrums. There is still a disturbance in him. That's why he's classified as emotionally disturbed. But he is coming out a lot. I just hope that Benito can get at least halfway through what Nei has gone through. Benito has come along, too. He is very receptive but not expressive. You can say things to him and he understands. Once, when everybody went upstairs and he wanted to be downstairs, he looked at me, and I told him, "I love, you, Benito." His eyes just filled with tears. It is very frustrating for me and for him, too. He wants to say things, but he just can't. When I tell him to get things, well, I can't use big sentences, but he can understand. He helps set the table. I haven't done any dish washing with him, but he can set the table.

I want to make his life as normal as possible. I want him to do for himself and not always have someone to do it for him. I want his needs met. It is true that it is hard when the handicapped have to use wheelchairs and crutches and other things. But he can walk, thank God! That's what I thank God for. He is good, and when you look at him, he seems normal. I want him to be part of our lives and of our little group. Everybody has to help. Even boys have to help nowadays. They all help. I have no regrets about marrying so young. It's just that if I had gone to school, I would be able to help Benito more today.

Introducing the Paiva Family

Mr. Del Valle, the special-education teacher, introduced me to the Paivas. During my first meeting with Mr. Del Valle, he mentioned a Brazilian couple whom he thought might be interested in participating in my study. The next week I saw Mr. Del Valle when I went to do the first interview with Mrs. Castelo. Mr. Del Valle told me that he had spoken to the Paivas and that they had agreed to meet me the following day. I met them the next day and explained my research to them. They agreed to participate, and we made arrangements for the first interview. We conducted the interviews in Portuguese.

Mrs. Paiva has four children. Elia, the youngest, is 21 years old and attends a special school for multihandicapped children. I did not meet Mrs. Paiva's other children. She told me that her two sons live with her. Bruno, their younger son, is single and lives in a separate apartment in the basement of the house. Her other son, Narcisio, is divorced. He and his five-year-old son Claudio live with the Paivas. The Paivas have another daughter, Dolores, who is married and at the time was living in another state.

Mrs. Paiva lives in a renovated two-storey house. One enters by climbing a few steps to a small covered porch. The front door opens into a small living room where I conducted the interviews. In this living room, there are two couches placed at right angles to one another and a television set that can be viewed from the couches. There is a small table in the middle of the room, and on the wall alongside the door is a small desk.

Elia is classified as having a "missing brain." The right side of her brain did not develop, and she has no brain tissue there. Because of this condition, Elia has seizures and takes medication to control them. She has the mental capacity of an eight-year-old. Elia's right leg is stiff; she drags that leg and walks with a walker. She cannot move her right arm above shoulder height and also has trouble using her right hand. In addition, she has a sight problem, and the right lens of the glasses she wears is noticeably stronger than the left.

I found Elia to be a very friendly and affectionate child. Her speech was normal, but she sounded as though she had phlegm in her throat. She asked many questions and seemed to be eager to do things on her own. Mrs. Paiva and Elia are often talking and embracing. Mrs. Paiva appeared very happy that Elia is an outgoing child who is loved by everyone who knows her, and she is interested in every aspect of Elia's life. Mrs. Paiva told me she has kept and filed every piece of paper that she has ever received from doctors, teachers, agencies, or social workers.

Mrs. Paiva's style of speaking about her child's handicap was very matter-of-fact. She told me that she was so used to talking about Elia and her handicap to doctors, educators, social workers, and others over the years that it seemed to her the most natural thing in the world to do.

Mrs. Paiva's Story

I have been in the U.S. for almost 38 years. I was eleven years old when I came. My mother had died during childbirth, and my grandfather brought my sister and me here with him from Brazil. My grandfather's wife wasn't well educated and worked as a domestic. She didn't have a lot of time to help me with my schoolwork, so I studied at the library or with friends and sometimes got help from the other members of the family. I went to elementary school, high school, and two years of college.

My husband has been in the U.S. since 1947, when he was seven years old. When we first arrived, there were very few Brazilians here. My future husband and I went to high school together. Then he enlisted in the marines and spent four years in the corps. I was working at the time, but when he left the marines, we got married. We have been married for 32 years.

I find life here very different--different because I think that people here are too preoccupied with material things. It's not that way in Brazil. People there don't have the same kind of life as we do here. There aren't many opportunities in Brazil. Even if people work, they don't have any possibilities for advancement. They can't get the things they want. If they do go to school, there are no jobs for them when they finish. It's different here. There are a lot of opportunities. Some people say there aren't, but I think there are. If you are willing to start at the bottom, you can advance from there, but the problem is that a lot of people want to start at the top. That's the difference.

The first time I went back to Brazil I stayed a month, and I didn't like it there very much. I even thought of never going back again. I did go back, however, and I liked it a little more. Now I visit every year and like Brazil. I'm used to the way they live there now.

You don't realize how practical and easy things are here until you go back to Brazil. I even found it difficult to get the things I needed in the supermarkets. I couldn't have a car, and there are cracks in the sidewalks. When I am in America, I live the way Americans do, and when I go to Brazil, I live their way. We have to adapt to things and places. It's a nice little life there. It's calm, it's fun, and the people are friendly. No matter how poor they are, they are willing to give you the shirt off their backs. Life is good here, too. Life is comfortable here, but we can't count on our neighbors to help us. If we have a problem, we have to solve it ourselves. That's the one thing I don't like about living here. I do, however, love living here.

When my handicapped daughter was born, she was a full-term baby but weighed only four pounds and five ounces. Five pounds is the normal weight, so she had to stay in the hospital. In the last ten days that she was there, the doctors noticed that her head was too big for her body and thought that she had water on her brain. She was transferred to another hospital where they examined her and told me that one side of her brain had not developed and was very dry. That's her problem. They call it "missing brain." Because of that, they told me she wasn't going to live very long. It was a shock for me because I thought I was going to lose her. Time went by, however, and she started to get better. She was developing, and I felt happy. The only big problem now is that she has seizures, but she takes medication to control them.

Well, she is somewhat retarded, too. She has the mind of an eight-year-old. Sometimes she is like a teenager, too. She loves music, tells me that she has a boyfriend at school, and wants her clothes a certain way. She fights with me when she wants something and I don't give it to her, or when she wants me to do something for her and I tell her that I'm not going to do it. She is developing, and she is growing. She is getting better every day. The only thing is that she can't do a lot of things by herself, and she can't really learn. If you teach her something today, she will forget it by tomorrow. She also has a problem with the right side of her body. She drags her right leg, and she can't lift her right arm up to her shoulder because her arm muscles are tight. She has the tendency to walk to one side, so she has a walker. She doesn't take the walker to school because they prefer to put her in a wheelchair there. I think that it is because they are afraid she will fall or something.

She also has a sight problem. Her right eye is very weak and she has to wear glasses. I think, however, that she is getting better and better every day.

When she was six months old, she first went to a cerebral palsy center. She went there until she was five years old. The bus picked her up and brought her home every day. When she was five years old, she went to the school where she is now. When she graduates, she will go back to the cerebral palsy center, except that she will be going to an adult recreation center. She will go there so that she has a place to go and things to do and doesn't stay home doing nothing. I don't want her to do just nothing.

Elia is a very cheerful child, and she is very pleasant and very friendly. She makes friends easily. Everyone likes her, and she likes everyone. I never thought of her as being my last child. I wanted to have more, but I had a hysterectomy because, although we are not poor, we are not rich either, so we didn't think that we could afford another child. I love children and wish I had more.

Today she is doing well, and I'm used to the way she is. She is really no trouble. She is as much trouble as a normal kid. I know what she likes and doesn't like. I know what she can and cannot do. So everything is going well. Whatever I can do for her, I will do. She has always loved school. She never wants to stay home. When Elia is home with me because of illness, she fights with me because she wants to go to school.

She is loved by everyone at school, and she gets along with everybody.

My place is here at home. I have to make dinner and get the children ready in the morning. This is the way the morning goes: I get Elia ready, I give her breakfast, make her lunch to take to school, and I get her ready for the bus. She has to be ready when the bus comes to pick her up. After she goes, I make breakfast for my grandson and get him ready for school, and then I take him to school. When I come back, I wash the dishes, clean the house, and go to the bank for my husband. He leaves everything ready for me to take to the bank. When the children come home from school, I sometimes give them dinner instead of a snack if they are hungry. That's the way my day is. I work in the house, work for my husband, and go pick up my grandson at school. That's what I do.

I have two sons and two daughters. My son, who is my grandson's father, lives here, but my daughter lives out of state. I have another grandson, my daughter's son. He is five years old. The other son lives here, too. Although my husband and I are not very intelligent, we have children who are very intelligent. I thank God for having such good children.

I'm already getting prepared for the future. Elia's future is with me. Either my daughter or my son's wife will have to take care of her if something happens to me or my husband. I think that she should be taken care of by a woman. I don't want to leave her with just anyone or just any place. Everyone knows her at the cerebral palsy center because she went there when she was little. The director knows her. I want her to go where everyone knows her and she knows everyone. She is going to learn how to set a table, play dominoes and checkers, to wash dishes, and to do the laundry. Things like that. Also, she will be with people who are like her, people with handicaps. This way she won't feel like she is different or inferior.

Elia's doctor always told me that these children are exceptional and they are handicapped, but they are also like the other children. They know exactly what they are doing and why they are doing it, so we need to treat them as normally as possible. There are very few places I go and don't take her. The only problem is that I can't take her out for an all-day outing because she takes medication and goes to the bathroom a lot. That can be a problem because some places don't have bathrooms. Everywhere I go, Elia goes. We go to Brazil together every year. She loves to go around June or July when there are a lot of parties for her to attend. People have asked me if I am afraid to take her to Brazil with me. If something happened to her there, perhaps they wouldn't have the resources we have here to help her. I tell them that I'm not afraid of anything. If something happens to her there, I think she could be helped; and if she can't be helped, I just have to live with it. I can't treat her so special, and I can't sacrifice my life and my husband's life. I thank God that I haven't had any problems with her. We go to Brazil, and she doesn't get sick or anything. Thank God!

Introducing the Xavier Family

Mr. Elias, from the local board of education, gave me Mr. Xavier's name. I was in touch with him and explained my research to him. He immediately agreed to be a participant. We made arrangements to meet at his home to discuss his participation. At this meeting, I explained my research to Mr. Xavier and his wife in greater detail. He signed the consent form, and we made arrangements for the first interview. Mr. and Mrs. Xavier both agreed to participate in the interviews, which were conducted in Portuguese. Mr. Xavier is a Protestant minister, and Mrs. Xavier is a housewife.

I found the Xaviers to be a friendly and outgoing couple. Mrs. Xavier seemed more easygoing than her husband. Mr. Xavier seemed more preoccupied with his work. He seemed to feel that the time he spent taking his son to school and back was cutting into his work time. He told me that he didn't mind taking his son to school, but it forced him to rearrange his schedule completely. Jorge usually took the school bus, but recently he has refused to do so. Mr. Xavier said that he suspected some kind of problem on the bus but had not yet found the cause. Mr. Xavier seemed all the more concerned because he told me that Jorge had always looked forward to going to school.

Jorge is the Xavier's only child. He has Down syndrome, is hearing impaired, and has hardly any speech. He seems to be somewhat overweight, but does not have the facial features that are so typical of so many Down-syndrome children. Jorge attends a school for children with multiple handicaps that is an hour's drive from the Xavier's home.

I met Jorge for only a few minutes after the first interview. He was watching a video. He said hello to me and immediately went back to what he was doing. Mr. Xavier told me that Jorge can become so engrossed that he can spend hours watching or listening, to the total exclusion of everything else.

The Xaviers live in a town that is just outside the city where the main Portuguese community is centered. They live in an apartment in a two-family, three-storey house with separate apartments on the second and third floors and a garage occupying the entire first floor. A high stoop leads to the second floor where a hallway and flight of stairs lead to the apartments. On the day of the first interview, the Xaviers were preparing to move from the upper to the lower apartment, which would give them use of the garage. The two apartments were almost identical. One enters a combination living room and dining room with a large picture window running across the front of the house. To the right, there is a corridor that leads to the bedrooms in the back of the apartment; and beyond this corridor, separated from the dining area by a low counter, is an open kitchen with modern appliances. I conducted the interviews in the living room that, once they were settled in their new apartment, was comfortably furnished with sofas and decorated with ornate copper utensils.

The Xaviers appeared to be very involved in all aspects of Jorge's life and education. Mr. Xavier's schedule seems to allow him to take the time to visit Jorge's school on a regular basis and to spend time with him after school. Mrs. Xavier, who was not working at that time, also spent a lot of time with Jorge after school. Of all the fathers in this study, Mr. Xavier appeared to be the most directly involved in his child's education.

Mr. and Mrs. Xavier were always both present for the interviews. For this reason, I have indicated which one was speaking for every change of turn.

Mr. and Mrs. Xavier's Story

Mr. Xavier: We first came to the United States about 20 years ago. I had received many invitations from churches to be their minister, but we were happy in Portugal. About seven or eight years ago, because of the problems with our boy Jorge, we started coming to the United States. We stayed here for a while, and then we returned to Portugal. Jorge was in school here, and sometimes we left him with friends. Then, about two years ago, we decided to make our home here in the States.

We did not come for economic reasons, not because we weren't doing well in Portugal. In fact, we lived better in Portugal than we live here. We came to the United States for no other reason than because of Jorge's problem. In Portugal, special education hardly exists at all, and there are no special courses to train teachers in special education. In Portugal, we have a lot of teachers who are very caring and full of goodwill but who just don't have the skills. Simply put, the quality of instruction is very weak. A highly placed official in the Portuguese Ministry of Education had the courage to tell me, "Please, go to another country, like the United States, for Jorge's sake." Several doctor friends of mine said the same thing. Even doctor friends in England advised us to come here, not just because of the special education, but also because of his health problems. We are here totally and completely to help Jorge. That's what we are doing.

In Portugal, I had a certain social position as an officer in a Protestant church organization. Here I'm nobody. I'm just the minister of a little church. I also worked one day a month as an economist consulting for a company. I am completely cut off from what was familiar to me. If it weren't for Jorge, we would be in Portugal. When he was little, they told us in Portugal that it wasn't worth teaching him and that we just shouldn't worry about it.

Mrs. Xavier: He has Down syndrome. He also has a chronic ear infection. He is a little retarded, like all children with Down syndrome. Someone who knows can tell he has it.

Mr. Xavier: We are trying to teach him to do everything he can for himself. We have a tendency to help him, but it's different in school. There he has to do things for himself. Jorge talks a little, so in school they talk to him and also use sign language at the same time. When he is angry, he makes the sign for "No" and the sign for "Be quiet," but only when he is angry.

Mrs. Xavier: When we first heard the news that he had Down syndrome, it's the kind of news that no one wants to hear, but we were prepared for it spiritually. We are Protestant believers. We really accept Jesus in our lives. We don't live alone. We are sure that we live with God. He accompanies us and guides us. He says He will never abandon us. He is a living God for us. God is with us in good times and in bad. When we got the news about Jorge, God was already there comforting us. As shocking as it is was for everyone, time goes by and it becomes real. We have accepted it, and we never resented it.

We do the best we can for Jorge. He is really enchanting to us: He gives us a lot of love, and he is very loved. He is a child who loves God. Even though we have this problem, it is difficult to think in terms of his future. We are very strong people, and we're not going to sit around crying. We have to keep in mind that our son has brought us a lot of happiness. We have seen normal children who always embarrass their parents in public. Our son has never embarrassed us. As a matter of fact, I wish that most of the normal children behaved as well as Jorge.

Mr. Xavier: Jorge has completely changed our lives. We try to live our lives as normally as possible. He likes to go to the mall and to McDonald's and to go for walks. If he were a normal young man, I would give him $5 and he would go wherever he wanted to go, but we can't do that with him. We have to take him everywhere.

Mrs. Xavier: Actually, it is a pleasure to do things with him.

Mr. Xavier: Having a handicapped child really changes a person's life. We have never left him at home. We used to travel quite a bit, and he always went with us. He went everywhere with us. If there was a party, he went with me. I found out that people liked it when he went with me. I used to tell people that I couldn't go to their parties because I couldn't leave my son alone at home, and they used to tell me to just take him with me. There are parents who are ashamed of their handicapped children. We are not at all ashamed of Jorge. Parents who don't have handicapped children just don't understand, just don't know. They have no idea how a handicapped child can change your life. Don't think that I feel miserable because of it, but it is difficult. I do everything because I want to, but we do have to adjust our life because of him. We can't live in this country the way that we want to live; we can't do the work we want to do; unfortunately, our life is a trauma.

Mrs. Xavier: We love to travel. We love to live in other countries and live with other people, learn about other cultures, but we can't do it now; we have to wait and do it later. Jorge is a loving child. He really doesn't look like he has this problem.

Mr. Xavier: He is a very neat child. He has a place for everything, and he has very good manners when he eats.

Mrs. Xavier: Sometimes people don't talk to him. It's not because they want to be mean, but he goes and says "Hello" to them. Sometimes when we have friends over and they don't say "Hello" to him, he goes and extends his hand for them to shake it.

Jorge loves videocassettes, especially church-related ones. He especially likes those sing-alongs, choir songs on video. There is a radio station here that has religious programs. They have educational programs and also have a lot of religious music. He loves to sing along with the radio. He also loves music. He has a little organ; he plays everything. After church on Sundays, he goes to the piano and plays. He plays everything by ear. If there is a party at school and they ask him to play the organ or the piano, he says "No." He plays only when he wants to, and when he says "No," he means "No," and no one can change his mind. He also likes children's videos like Beauty and the Beast. I am always looking for things for him to do and learn about. At home, he likes to set the table; he does a lot of things. He is really a good kid, and he is very helpful. He is the one who brings my briefcase into the house. He collects the hymn books in church. He helps with communion (he brings the bread); he also brings the plate with the offerings to the office. Everyone knows that these are Jorge's jobs in church.

Mrs. Xavier: Jorge loves to go out. He loves to go to the supermarket. He likes to do things very slowly, and sometimes we don't have time for that. He also loves to look at books and photographs.

Mr. Xavier: Jorge is very close to me. I think that he is closer to me than to his mother. What's more, I'm the one who shaves him and who takes him to school. Because of that, he feels a certain closeness to his father.

I think that I'll stay in America another four or five years and then I'll go back to Portugal. In four years, we will be able to see if Jorge has some kind of job that suits him, either working in a supermarket or in a workshop. In that case, we wouldn't go back to Portugal. If not, if there is nothing for him, it's not worth staying in the United States. The cost of living here is very high. Our economic situation here is not as good as it was in Portugal. What I want to say is that we could give him more in Portugal. We have to think what is better for Jorge, what is in his best interest. Would it be better to be there or to be here? Frankly, I am here only because of him. Otherwise, I would not be in America. I would be in Portugal.

Mrs. Xavier: We have to see what happens with him here in this country. If they say that he is doing very well at a certain job, then we will have to think twice. By now, he is really an American. He came here when he was really young.

Maybe he wouldn't feel as comfortable in Portugal as he does here. I don't know.

Introducing the Duarte Family

Both Mrs. Castelo and Mr. Xavier told me about the Duartes and their special-needs son. Mr. Xavier knew about the Duartes through Mr. Elias from the board of education. Mrs. Castelo knew the Duartes because she had worked for them as a teenager. The Duartes own a chain of coffee shops. Both Mr. and Mrs. Duarte are involved in running the business, and they are very active in the Portuguese community. Their business and community activities seem to take up most of the Duartes's time.

I first tried to make contact with the Duartes by visiting one of the coffee shops. There, an employee told me to try one of the other shops. At that shop, an employee told me to try them on another day. It went on like this for several tries until finally an employee told me that my best chance of seeing them would be by going to the main coffee shop where their offices were located. I went to the main office unannounced one afternoon in the hope of getting to speak to Mr. Duarte. At that time, I did not know that Mrs. Duarte was also active in the business. When I entered the office and asked to speak with Mr. Duarte, the receptionist asked me what company I was with. After I thought, I gave them the name of the university where I'm getting my Ph.D. Without knowing it, this was the key that would give me access to the Duartes. A few moments later, Mrs. Duarte came out to speak with me. I introduced myself and briefly described my research. She immediately asked me to come into her office for a further talk.

First, Mrs. Duarte took me into her husband's office and introduced me to him and to her older son Bernardo, who is also active in the family business. We then went into her office and sat down to talk. I gave her a flyer and explained my research in detail. She expressed an interest in participating, not only because her younger son Carlos is a special-needs child, but also because her older son Bernardo had graduated from the same university that I was attending and was thinking about going back for a Ph.D.

Mrs. Duarte also told me that she knew several other families with special-needs children. She said she would give them my flyers, encourage them to participate in my research, and let me know about their interest at the time of our first interview. We made arrangements to conduct that interview the following week at her home, at which time she would sign the consent form. During this preliminary meeting with Mrs. Duarte, we spoke English. The interviews themselves and most subsequent conversations with Mrs. Duarte were in Portuguese.

Mrs. Duarte has three children. Fernanda, the oldest, is in her late 20s. She is a nurse and was a newlywed at the time of the interviews. I did not have a chance to meet her because she was working at the time. Bernardo, the middle child, is 24 and works in the family business. Carlos, the youngest, is 21 and is in special education. He was just about to graduate from a school for children with multiple handicaps.

Carlos is classified as learning disabled. Mrs. Duarte reported that the doctors never really told her the exact nature of his learning disability. She said they told her that Carlos might have Down syndrome because of a history of Down syndrome and retardation in her husband's family. Looking at him, Carlos seemed to me to have mild Down syndrome. He is short in stature and has a roundish body without being chubby. He also wears fairly thick glasses.

The Duartes live in an apartment in the same building as their office. This building also houses one of their coffee shops and the central production and distribution facilities for the entire chain. The Duartes's apartment is on the second floor of the building above the offices. It can be reached from the outside by a separate entrance with a staircase leading directly to the apartment or by a staircase from the office.

The Duartes's apartment is quite large. From the front door, a long, narrow hall runs almost the entire length of the apartment. As one enters, there is a dark but well-furnished living room to the left with one window at the front of the building. The living room connects to a large, bright dining room. To the left of the dining room there is a large conference room with a long table and a bar. Beyond this conference room, there is a family room with a television. I assume that the bedrooms, which I did not see, lead off the conference room. The large kitchen is at the end of the narrow corridor next to the dining room. The first two interviews were conducted in the dining room, the third in the conference room.

I met Carlos for the first time briefly during the first interview. At that time, Mrs. Duarte told me that he was "lord of the manor." "Yeah," said Carlos, agreeing with her heartily. On the day of the second interview, it was Carlos who met me at the door and took me upstairs. He sat with us and asked questions about my research. After I explained my research to him, he wanted to see the questions that I was asking. He looked at them, said they were interesting, and then changed the subject. He started talking about his favorite sports teams and was very enthusiastic because one of them had recently won the championship. Then we talked about his school, especially about the part-time jobs that were part of his program. He also talked about his after-school job in the family business. I found Carlos to be very friendly and articulate when talking about subjects that interest him. His speech, while very clear, had the staccato quality that I had often found in the speech of autistic children with whom I have worked.

During the first interview, I did not feel very comfortable with Mrs. Duarte and had the impression she did not feel very comfortable with me either. Her answers were short, and I had to pull things out of her. However, once we started talking about Carlos, she seemed to change. I felt that she loved to talk about him and what he was doing. She showed me a thick folder that contained Carlos's art works and several news clippings about Carlos at school. She made copies of some of these for me.

Mrs. Duarte said that she was active in many Portuguese cultural and community organizations as well as in organizations for the handicapped. Several of the other participants later told me that Mrs. Duarte had been a great help to them when they were trying to find schools and services for their own handicapped children. Mrs. Duarte's influence in the community is borne out by the fact that she introduced me to four other mothers, all of whom participated in my research. Not only was she influential in her community, but she was also a big help to me.

Mrs. Duarte's Story

My life in Portugal was very similar to my life in the United States. My father had the same type of business that we have here. My mother was an elementary-school teacher, and my grandmother was a professor at a university. I'm the oldest of nine brothers and sisters. I have seven brothers and one sister. She was born when I was 18 years old. After school, I used to help my father in his business and my mother with my brothers and sister. I always had a very active life.

I think I was privileged because not only my grandmother but also my mother were teachers, so I knew how to write by the time I was four years old. By the time I started school, I could write and do a lot of other things. In those days, there were schools for boys and schools for girls. Now there are a lot of coed schools. My mother was never my teacher because she taught at the boys' school where she taught all of my brothers. The teacher I had is still alive but is not teaching anymore. I still visit her every time I go to Portugal because we have always been good friends.

My husband's older sister was Mongoloid. She died when she was 45 years old. Unfortunately, in Portugal at the time, the doctors never really examined her, and things weren't as advanced as they are today. My sister-in-law lived a very isolated life. Her father never let her go anywhere. He was kind of ignorant about this sort of thing, and we never really knew what kind of problem she had. However, when we look at photographs of her and look at her mannerisms, we can see that she was Mongoloid. There was another person in my father-in-law's family who was retarded, but she was from a previous generation.

Carlos has been seen by many specialists, but they never really told us what his problem is. They think because of my husband's family history that Carlos has Down syndrome, but they have never said so definitely. They did a genetics test and many other tests, but all the doctors said was that Carlos has many abnormalities. He is brain-damaged and has poor coordination in his hands.

I never really felt bad about having a handicapped child. It was difficult in the beginning, but I accepted it. It was, however, very hard for my husband. I always did whatever the doctors told me to do for Carlos. When Carlos was born, the doctor never told me that he had a problem. When Carlos was two months old, I noticed that he was different from my two other children. I knew that something was wrong, but I just didn't know what it was. So I took him back to the doctor. I asked the doctor if anything was wrong with the baby because he never cried. She started to laugh and said that maybe the baby just didn't like me. I felt very hurt and depressed when she told me that. I had a lot of experience with children. I had also noticed that he wasn't growing and he just wasn't developing. When I told her about it, she looked at me and told me that I was imagining things and there was nothing wrong with Carlos.

When Carlos was six months old, I took him back to the doctor. Carlos was sitting up by then, and she said, "See, he is sitting up. There is nothing wrong with him." I took Carlos to another doctor and told him what had happened with the first doctor. This doctor looked at Carlos and said that there was definitely something wrong with him. He examined Carlos and told me that his ears were lower than they should be. He saw a lot of little things that seemed to be wrong with Carlos. The doctor said that he had to run some tests, and he needed information about my family and my husband's family, so I told him everything. He asked me if I had had measles or if I was around anyone who had measles when I was pregnant. He asked me about my pregnancy, and I told him that it was normal.

This doctor is a child neurologist. I like him very much because he is honest and sincere. When Carlos was five years old, this doctor told me that when Carlos was conceived he must have had a touch of Mongolism. He said that because we had those two other cases in my husband's family, it was probable that Carlos had Down syndrome because that kind of thing usually skips a generation. I have taken many people with handicapped children to him. He is really a great doctor.

I have always accepted Carlos the way he is. After all, what could I do? I thank God that Carlos is the way he is. It could be worse. Carlos is really special. We at home think that he has brought our family even closer than we were. We are all very close to Carlos.

We have always lived above the business because I could be involved in the business and still take care of my children. I struggled to find the right school for my son. It was the neurologist who first told me about the school where Carlos is now. First, we put Carlos in a regular private school. The principal of that school told us that Carlos might need a special school. His neurologist gave me a list of special schools, but told me that the school that Carlos is in now would be the best for him.

It is hard for Carlos to do a lot of things. He even has trouble signing his name. It's hard to understand; he can remember in detail something that happened ten years ago and forget something that we told him to do five minutes ago. You might think by looking at him that he couldn't even carry on a conversation, but he can. However, he can talk about only the things with which he is familiar. For example, if you ask him about his favorite teams, he is able to give you all the statistics for the last ten years. He reads the sports pages every day. Carlos participates in the Special Olympics and even won a gold medal this year. In a lot of ways he is normal, but he seems to have some autistic characteristics. The doctors have never said so, but it seems that way to me.

Carlos really likes music. He has a radio and a compact disk player. He likes to listen to music when he is taking a bath and before he goes to sleep. Carlos also likes to go out to the movies. On weekends, his brother, his sister, or his father and I take him. He also loves to socialize. We always take him with us to weddings and parties when we go as a group. He doesn't like to go places by himself.

We go to Portugal every year, but only for a week at a time. Carlos has stayed there longer with my mother. Then either she or my brother came over and brought him back. Carlos loves to go to Portugal. I think it's because he has more freedom there and because he is very fond of one of his uncles there.

After Carlos finishes school, we don't want him to go to one of those workshops. My husband has already said that he will find Carlos a job in the business when he finishes school. He already helps with the payroll and does a very good job. We always check on what he has done, but he doesn't make any mistakes. He has been an inspiration to us all. I think that Carlos has encouraged his brother and sister to do the most they can with their lives.

Of all the people in the family, I'm the one who Carlos opens up to the most. Things that Carlos won't tell his father he will tell me. Sometimes, however, he won't open up at all. Lately, he has been very sad, but he won't say why. I have an idea it is because he is leaving the school where he has been for most of his life. Yet sometimes I think he is sad because he realizes that his life will never be the same as his brother's and sister's. Carlos wants so much to be able to drive a car, but he just can't. I have tried to explain to him that people are different and that not everybody can do the same things.

Sometimes Carlos doesn't feel well, but he doesn't tell me. I tell him that he has to let me know when he doesn't feel well because it is the only way I'll find out. He tells me not to worry about him. He said if he dies, he will go to paradise. He is very sensitive.

Introducing the Carvalho Family

I got to know Mrs. Carvalho through Mrs. Duarte. Their sons had attended the same special-education school. Mrs. Duarte informed Mrs. Carvalho about my research and sent her one of my flyers. When Mrs. Carvalho expressed an interest in participating in my research, Mrs. Duarte gave me her telephone number. I called Mrs. Carvalho, and we made arrangements for a preliminary meeting. At this meeting, I explained my research in greater detail, and Mrs. Carvalho agreed to be a participant. When it came time to sign the consent form, however, Mrs. Carvalho expressed misgivings about having the interviews tape-recorded. She said that she was willing to answer any and all of my questions, but she did not want to be recorded. She told me that no one had ever discussed with her feelings about having a child in special education or about participating in her child's education. She signed the consent form, but scratched out the part about being recorded. I acquiesced in her wishes, and we made an appointment to meet for the first interview. We conducted these interviews in Portuguese.

Mrs. Carvalho lives in a town that is just across a river from the city with the main Portuguese community. She lives in a two-storey house with a garage on the first floor and apartments on the second and third floors. Many of the newer houses in this area have that layout. Mrs. Carvalho lives in the second-floor apartment, and her sister and brother-in-law live on the third floor. The garage has been converted into a studio apartment for Mrs. Carvalho's younger son, Silvio.

The front door of Mrs. Carvalho's house is reached by an L-shaped flight of stairs on the left side of the façade. You then enter a small vestibule with a flight of stairs leading to the third-floor apartment. The door to Mrs. Carvalho's apartment is to the right as you enter the vestibule. This door opens into a living room with a large window across the front of the house. There is a couch against the wall facing the door with a recliner angled between the couch and the window. To the left of the living room is an open dining room with a long dining table. Against the back wall of the dining room is a china closet filled with Portuguese crystal and porcelain. On the left wall is a sideboard within which Mrs. Carvalho displays various silver serving dishes that she told me were wedding presents. We conducted the interviews in the dining room.

Mrs. Carvalho has two sons: Silvio, who is 20, and Quim, who is 22 and has cerebral palsy. Quim attended a special school for children with multiple handicaps. He is now at a workshop for handicapped young adults, doing assembly-line type work. He is short, about 5'4", a little overweight, and has trouble walking because of his disability.

When I met Quim, I found him to be a very outgoing, friendly, and affectionate person. He loved to give as well as receive hugs and kisses, and he held my hand through the whole time that we were together. Quim's speech, while intelligible, was not always clear, and he had trouble forming words. He appeared to love to talk and tell stories. Most of the stories he told me were about religion and Our Lady of Fatima. He told me that he loves to go to movies and parties, but what he loves to do most of all is to help other people who also have problems.

Quim and his mother appeared to be very close. They were always talking to each other about their thoughts and feelings and about what went on in their lives. Mrs. Carvalho appeared to be a very active person. She was involved in many organizations for the handicapped, as well as organizations and programs in the Portuguese community. Although she said that she does not want to go back to Portugal, Mrs. Carvalho expressed concern about Quim's future in this country and seemed to feel that he would do better in Portugal.

Mrs. Carvalho's Story

I have been in this country for 27 years. We came because my husband was offered a job here. We weren't married then, but when he was offered this job, we were quickly married so I could come also. After a while, I sent for my nine brothers and sisters. We are 13 all together.

In Portugal, I had a good and comfortable life, but my husband had always wanted to come to the United States. When we first got here, I went to work at a factory. It was horrible for me. I began to like it a bit when I started to work with clothing. After that, I went to work for a big company, and I really liked the work there. After I had Quim, I stayed home for a while and then went back to work.

Life here in the United States is very different. It is a different environment and a different language. It was hard for me to learn English. We went back to Portugal for the first time around Christmas. While there, I realized how good it was that we came to the United States. There are a lot of opportunities here. When I realized that, we came back and bought this house. We have been in our house for 26 years.

Quim has cerebral palsy. I went back to work after he was born, but then I saw that there was something wrong with him. All of my brothers and sisters have perfect children. The children are also perfect in my husband's family. I was the only sister who had a child outside of Portugal and also the only one with a child with a problem. I started to notice that Quim couldn't drink milk from a bottle, and I had to use a little spoon. I also noticed that he had a limp neck and couldn't raise his head. He didn't seem to have any strength in his arms and legs so he couldn't crawl or stand up. I took Quim to a doctor who told me that Quim was careless and lazy and there was nothing wrong with him. All the doctor said was that Quim was slow in developing. Then, when Quim was getting older, I noticed that he didn't walk and he didn't talk. He couldn't stand up and he couldn't sit down without falling, so my husband made these straps with a little pillow for Quim's chair that supported him so he could sit without falling.

My sister took me to another doctor. As soon as he saw Quim, he told me that Quim had cerebral palsy. I started to cry. I couldn't understand why I had a sick child. Life was already difficult, and when we had the misfortune of having a child like this, it was very sad. He was already two and one half years old and he didn't walk or talk. He didn't do anything. It was very sad. The doctor asked me who Quim's first doctor was, and I told him. He asked me, "The doctor never told you that your child has a problem?" I told him "No," and he said, "I don't understand; I know this doctor, and I don't understand why he didn't tell you." I started to cry again.

Quim went to a cerebral palsy center when he was already three years old. They did a lot of therapy on his little legs. They also told me that since the doctor had said Quim had strength in his legs, it was possible that he could walk. Quim went to that school every day from 9:00 until 11:00 in the morning. I had to take him there and pick him up, so I stopped working. The school was expensive. Since I had to take him there every day, I didn't have time for anything else. When I'd get home, it was already time to go back to pick him up. One day I asked the teacher if I could stay there, and she said it was okay. I took a book with me to read, but I didn't really read it. I wanted to watch them do the therapy with Quim because I wanted to learn how to do it. The teachers didn't think that I was watching them, but I was really watching everything that they were doing with Quim. I liked it there because the teachers did a lot of therapy on Quim's legs and arms. They were always saying that Quim was going to walk. What I didn't like about the school was that it was dirty.

When I got home and after Quim woke up from his nap, I used to do the therapy that I had learned from the teachers. The teachers were very good with Quim. One day he just started to walk. The teachers also told me that Quim was improving more than they had expected. That was when I told them that I was doing the therapy at home, and they asked me, "Did you take a course in therapy?" I told them "No," that I learned from watching them. Then they said, "Do it here the way you do it at home so we can see if you are doing it correctly." I told them that I must have been doing it correctly because they said that Quim was improving. I showed them how I did the therapy at home, and they told me that I should continue to do it.

Quim started to walk not by himself but by holding onto a table. I didn't remove anything from the table; all I did was move everything toward the center of the table so he could have more room for his little hands. People are always telling me, "You have such good children." I tell them that it isn't just their nature that they are good children, but it is also how parents raise their children. I think that children nowadays don't have any respect for their parents or anybody else.

When my younger son Silvio was little, he didn't understand that Quim was sick. He used to ask me, "Mom, why is Quim this way?" I tried to explain it to him, but he couldn't understand it very well. When he got older, he could understand it better. Silvio is a very good friend to Quim and loves him very much.

After two years, I noticed that the school wasn't doing very much more for Quim. He was walking, but he wasn't doing anything else. I called the board of education, and they assigned Quim to another school. There the teachers told me that it was possible that Quim could learn to talk, and they started to do therapy on his tongue. They also started to teach him sign language. They told me that I had to learn it so that I could communicate with him. One day I gave him bread and said, "bread," and he said, "bread." I then asked my mother, "Did you hear him say bread?" and she started to cry. It was then that I realized that Quim was talking. I went to the school and told them to stop doing the sign language with Quim. It was then that they asked me what language I spoke at home. I told them it was Portuguese, and they told me that if they stopped using sign language, they wouldn't be able to communicate with him. I told them to teach Quim to speak. They told me to speak only English with Quim. I told them that I didn't speak English very well, and I didn't want to teach him to speak incorrectly. They said, "Ah, this way we can't communicate with him. He says one word in English and one word in Portuguese, and we don't speak Portuguese." I didn't like that at all.

Another thing I didn't like was that when the board of education called to ask me if I was happy with the school (they were very good about calling to find out how things were going), I told them that my son and another little girl who lives near us were the only ones who could walk in the school, and I was worried that Quim didn't want to walk because all the other children were in wheelchairs. I also told them that I didn't like it that the teachers didn't want me to speak Portuguese with Quim. They gave me another school. When I got there, I thought, "This is a good school for Quim." He stayed at that school until he graduated. My son learned a lot there. There were no elevators at the school; there were a lot of stairs, and all of the children had to walk. That school was very good for Quim.

I did everything I could at the school. I couldn't do more because I had another child at home who went to another school. I had to take Quim to school and pick him up. Quim used to love that school. He cried when he had to leave it; he didn't want to graduate. He just wanted to stay there; everyone liked him, and he liked everyone. He always talked about school: what he did, who his friends were, the teachers whom he liked.

Now he goes to work, but he doesn't say anything. I think he goes to work only because he can get out of the house. He loves to be with people. Everybody knows him around here. He has a tremendous imagination and tells lots of stories. It is really impressive sometimes. Now he goes to this workshop, but I don't really like it very much because I don't think he is doing a lot there. It's only a place for him to pass the time. I think that the government should have better things for handicapped adults, but they don't. I think that I should have gotten a private tutor for Quim when he was in school. Maybe if I had a tutor at home, he would have learned to read and write. I don't know, but that's what I think I should have done. It's too late now, but I should have done that.

Quim is a very religious child. He always goes to church, and he loves Our Lady of Fatima. He promised Our Lady of Fatima that he would take her flowers every time he goes to Portugal. It has to be white flowers. It just can't be any other color. White flowers, you see, are his favorite. Quim loves God, and we always go to a sort of catechism. It is a kind of a religion class where we pray and we talk about religion.

When Quim comes home from work, he doesn't want to do anything, but at night he is active in a lot of organizations for the handicapped. Quim loves to go out and talk to everyone, and he loves food just like his father; but when he is out at a restaurant, he doesn't eat much because he prefers to go from table to table to talk to people.

Quim loves to speak Portuguese. He speaks both English and Portuguese very well. My younger boy doesn't like to speak Portuguese. Quim loves to go to Portugal, but Silvio doesn't. He is more Americanized. We always go to Portugal in the summer for three or four weeks. We also go at Easter, but we don't take Quim. He stays with my sister who lives upstairs.

I don't like the way that people look at Quim in Portugal. I don't think I could live there because they are still a little ignorant. They still think that a handicapped person should be kept at home and not do anything. When we go out in Portugal, people stare at Quim, but he doesn't say anything. Americans don't do that. They always want to help handicapped people. I like to vacation in Portugal, but I don't know if I could live there. Handicapped people are treated much better here.

Look, I'm not going to say that it was easy having a handicapped child, because it wasn't. When Quim was little, I just couldn't understand why he was this way. I always said to God, "Why do I have a child like this? I always go to church; I have never done anything bad to anyone. Why did this happen to me?" Quim doesn't like to hear me talk like this, but I think he has to know. He has to understand that it was not easy for me. I never thought I would have a child like this. When I realized that he didn't walk and he didn't talk, it made me very sad and I rebelled. I didn't go to church anymore. One day I was talking with my sister, and she told me that sometimes God does this to see if people are truly strong and patient. She said:

> You know, Gloria, God protects the people who have children like this. Don't think that it is a punishment, because it isn't. He only wants to see if you are strong.

I started to understand it more and more. I can accept Quim the way he is now, but when he was little, it was very hard. I just couldn't believe it. I kept telling myself that he was going to get better. Well, he did, but not the way I thought. Now I can accept him the way he is. To say that he was a positive thing in my life, well, I can't say that. With time, however, I saw that Quim was helping me to be a more caring person and a person who wanted to help other people who had problems. I wasn't like that at first. The only thing that I worry about now is his future. I don't know what would happen to him if I died. I don't want Silvio to have to take care of him.

My husband is thinking of going back to Portugal. We have a house on the beach, and Quim loves it there. I think I also want to go back to Portugal, but I don't know. We are still thinking about it. I worry about everything. We think it might be better there for Quim, but I don't know.

My husband gets up very early. I don't get up with him. He goes to work at 7:00 in the morning, but before he leaves, he makes his own breakfast. Then Quim gets up and gets dressed and has his breakfast because he has to leave by 8:30 when a school bus comes to pick him up to take him to the workshop. I get up when he leaves and get ready to go to work. Then at 3:00 in the afternoon, I go back home to wait for Quim. I like to go out with Quim when he gets home from school. I don't like to have him sitting in front of the television. He is always very active. I never let him just do nothing. After dinner, I sometimes watch a movie or do work that I bring home. I'm never still and am very active. I have always been this way.

My husband always says, "I don't care what you do when I'm at work, but I expect the children to be taken care of and dinner on the table when I get home." My husband doesn't like me to do anything in the evening unless it includes him and/or the children. I have gotten used to his ways, and I like it. My husband is a very good father.

You know, although we treat Quim as if he were normal, he has to understand that there are some things that he can't do like a normal person and that he needs help. I always talk to

Quim. He is a very positive person. He always sees the positive side of things. He doesn't like to see the negative side. There is something that he does that I find very strange. When he goes to parties with his friends who are also handicapped, he never dances with the girls who have problems like him. He dances and talks only to the girls who are there to help them. These are normal girls. He told me that at work he talks only to the lady who is there to take care of them, because he doesn't like to be with people who have problems like his. He said that he goes to these places only to get out of the house. I find this very strange. I have asked Quim about it, but he says that he doesn't know why he feels the way he does. I want him to learn and do things that are good for him and not things that make him unhappy.

Introducing the Dias Family

I met Mrs. Dias through Mrs. Duarte, who had helped Mrs. Dias find a school for Nelson, her special-needs child. Mrs. Duarte called Mrs. Dias to explain my research to her and then sent her one of my flyers. Mrs. Dias contacted me, and we made arrangements to meet at one of Mrs. Duarte's coffee shops. She later told me that the reason she wanted to meet at the coffee shop was that her older daughter worked for Mrs. Duarte after school, and Mrs. Dias often met her own friends there after work.

At this first meeting, over coffee, I explained my research to Mrs. Dias, and we also discussed the consent form. She told me that while she found my research interesting, and would participate, her main reason for doing so was because Mrs. Duarte had done so. She said that if Mrs. Duarte felt that it was important to participate, so did she. Mrs. Dias indicated to me that she did not want to be tape-recorded. When it came time to fill out the consent form, Mrs. Dias did not fill in her address, although she later gave it to me. She told me I could use any and all the information she gave me that I could remember. We made arrangements to hold the first interview the following week at the same coffee shop. We met in the late afternoon, after Mrs. Dias had finished work in a factory. We conducted the interviews in Portuguese.

All three interviews were conducted at this coffee shop. We always sat at a table in the rear of the coffee shop next to a large window and across from a long counter. The coffee shop itself was bright, modern, and well-lighted. There were always a lot of people there at this time of the day. By sitting at the back, we had more privacy, and Mrs. Dias seemed comfortable talking to me there. Mrs. Dias was the only participant whose home I did not see.

Mrs. Dias has three children: Tania, who was almost 17 at the time of the interviews; Nelson, who was 15 and is a special-needs child; and Jane, who was twelve years old. Nelson has Down syndrome. He attends a special school for children who have multiple handicaps.

I met Tania, Mrs. Dias's older daughter, when she came to meet her mother when her own after-school job was finished. Tania seemed to be friendly and very inquisitive. She wanted to know about my research. After I explained it to her, she enthusiastically encouraged her mother to participate. During the third interview, Tania was with us for about half the time. She even participated by telling stories about Nelson and making observations and expressing her opinions on various topics. She seemed most interested in how participation in Nelson's education affected both him and their mother.

I met Nelson at the end of the third interview when Mrs. Dias's husband brought the whole family to pick her up. Mr. Dias brought the children especially so that I could have an opportunity to meet them. I really only had an opportunity to say "hello" to Mr. Dias and to Jane, their younger daughter, who left almost immediately. Nelson stayed so that I could get to know him a little better.

Nelson is short and has a squarish body. By looking at his facial features, it is not obvious that Nelson has Down syndrome. He seemed to be very friendly, but only offered to speak if someone else initiated the conversation. His speech was not very clear, but this did not deter him from speaking. Nelson was eager to talk about his collection of toy cars and the belt he was wearing, which was hung with several keys, a beeper, key chains, and small good-luck charms. He spoke English to me, but his mother spoke to him in a mixture of English and Portuguese.

Mrs. Dias said that although she loves all three of her children, she felt a special kind of love for Nelson, and she wanted to do everything possible to make him happy. Even though Mrs. Dias seemed eager to talk about Nelson, it was more difficult to get her to express opinions on other topics. Whenever I asked her to talk about something other than Nelson, she would start to look out the window and fidget with objects on the table. It appeared to be a real struggle for Mrs. Dias to form her thoughts and find the right words to express herself. I became very frustrated watching her struggle, and had to walk a fine line between facilitating her responses and putting words in her mouth. I was also frustrated because I could not tape the interviews. When we were finished, Mrs. Dias told me that if she had known beforehand what the interviews were going to be like, she would have allowed me to use a tape recorder.

Mrs. Dias's Story

I have been in this country for 21 years. One of my mother's brothers, who already lived here, sent for me and my mother. My uncle always told my mother that we should come because we could have a better life here. We came to better our lives. I was only 16 at the time. My mother, poor woman, was already 64. We are ten in our family, but only seven are in the United States. The other brothers and sisters are back in Portugal. I was just a kid in Portugal. I went to school and helped my mother at home. When I arrived here with my mother, I went to work right away. I didn't go to school anymore. I got here on a Friday and went to work the following Monday on an assembly line, or something like that. I didn't like the work, and later I went to work in another factory.

My mother didn't work in this country because she was somewhat old. I worked to help my mother with expenses. Soon my mother went back to Portugal. After that, I went to live with my uncles. After I learned to use a sewing machine, my uncle found me another job at another factory, and I'm still working there. When I went to live with my uncles, I also helped them with expenses. When I had enough money, I sent for some of my other brothers and sisters.

I married a Portuguese man whom I had known for a long time; we grew up together. We got married in Portugal and then came back to the United States. We bought a little house and had three children. My husband worked with boats, or something like that. He had an accident, and . . . he can't work anymore. He stays home now and helps a lot, the poor man.

Nelson, my child with the disability, is a very happy child. He loves cars and has bags and bags of miniature cars. He won't go to sleep unless all the bags of these cars are around his bed. He has Down syndrome and despite this problem is very intelligent. My oldest daughter is a very good friend to him, and he is a very good friend to her. They do everything for each other. My younger daughter is not very friendly to Nelson. I think that she is jealous of him.

I love to talk about my son. He is a very special person to us. My husband says that Nelson is the "Baby Jesus." Nelson means everything to us. You can't imagine how much love we have for him. He is my angel. A lot of people don't understand these children. These people look at these children with pity. They just don't understand and are ignorant. Sometimes I see mothers of normal children on the street who treat their children badly. The children are sometimes dirty and don't respect adults. It is then I think that if these people had handicapped children, they wouldn't know what to do with them. If they don't even know how to take care of normal children, they wouldn't be able to take care of a handicapped child.

At first I didn't notice anything was wrong with Nelson, but my husband did, and after a few weeks the doctor told my husband and me that Nelson had Down syndrome. After all that, I started to notice that he was different. He was always getting sick and was often in the hospital. One day he would be home, and then he would spend three or four days in the hospital. He didn't die because I think that God didn't want him to die. It was a miracle that he didn't die. It wasn't time for him to die. God wanted us to take care of him. God knows how much we love Nelson. My husband does everything he can for him, and so do I.

When Nelson was two and one half years old, it was Mrs. Duarte who helped me. I already knew her. Everyone knows her because she loves to help people. She took me everywhere--to the board of education, to the Social Security office to see if they could help me, to visit a school. When Nelson went to his first school, he was just a little boy. I don't remember it very well, because he was so little, but I think that he had speech therapy there. He doesn't speak very well, but he does speak. His class was small. There were only six to eight students. The school bus picked him up and brought him home. The teachers were very good with him. I don't think that Mrs. Duarte would recommend a school that wasn't good.

Nelson stayed at that school for many years. Then, when he got older, I saw that he needed something else. So I went with Mrs. Duarte to the board of education, and they assigned the school where he is now. I'm not certain, but I think that it has a work program. At this school, he learns to cook, to bake cookies, and to wash clothes. I think that he has what you would call job training. He can work, and he learns things very quickly. When he goes to a place for the first time, he never forgets it. One day we were near a street where he worked one summer, and he said, "I have been here before. I used to work here." Sometimes I am really impressed by him.

Nelson loves to go to Portugal. I think that he feels free there. He can walk around everywhere, and the people there know him and know how he is. No one in Portugal treats him as different. They all treat him like a normal person. They never talk to him as if he is a handicapped person. We also treat him normally. Of course, he can't do a lot of things that normal people can do, but we never treat him any different than the other children.

Nelson does a lot of things at his school, but he will go to another school soon. The other school is also a school for handicapped children, but they are not severely handicapped. They can work. They sent me all the papers, the directions, and the phone number, but I don't know if I'm going to put Nelson there. I have to call for an appointment. If I like the school and if Nelson likes it, then he will go there. I think that Nelson will go there because it is better for him to be in a more normal school. This way he can advance more. I think that if Nelson stays where he is, he might get more behind because where he is now there are a lot of children who are more behind than him. I don't want that; I want Nelson to be able to work and have a good life. He will be going to high school. It is like a vocational school. I don't really know. I don't know where the school is, and I don't even know the name of it. I just received the papers a few days ago, but I haven't had time to read them yet.

It's hard having a child in special education, not because Nelson is handicapped, but because he is in a school like that. I am very sad that he is there. I don't like to talk or even think about it. First of all, they really encourage Nelson. I like that, but if Nelson were in a school that didn't have so many handicapped children, maybe he could advance more. Another thing that I don't like is that these days so many things happen in the schools that I keep thinking: Are they treating my son well? There are so many stories about schools abusing children that I get worried. I think that if something happened, Nelson would not be able to defend himself or tell me what happened. With the girls, it's different. When I ask them what their day was like, they tell me everything. But with Nelson, I never know what goes on because he doesn't know how to tell me. I can't accept that he has to go to a school like that. That's why I want to visit the other school that seems more normal. The children aren't more handicapped than he is. I think that Nelson will do better there because the teachers will encourage him more. I don't know, but I hope so.

My children are in three different schools. Tania is in a private school. She finds it very difficult. Jane is doing well in a public school down the street where we live. I think that it is easier for her there. I already tried to put her in a private school. She went there for a year and then told me that it wasn't for her. Now that I'm working and my husband stays at home, he is the one to make sure that they do their homework. It's their responsibility to do their homework.

I get up early and get the kids' clothes ready and make them breakfast. I don't like it if they go out without breakfast. When the kids get home, they do their homework. Nelson doesn't have homework, but he draws, or if it is a nice day, he goes out to play with the other children in the neighborhood. Nelson likes to be with them. He is a very happy and sociable person. Everybody likes Nelson. When I get home from work, I have to make dinner. Sometimes my husband gets things started. Afterward, I have to do the laundry . . . stuff like that. After dinner, Nelson, my younger daughter, and I clean the kitchen. When that's finished, if there's time, we watch a little television; if not, we go to bed. That's what my life is like. It's hard to work and take care of children and a home. I thank God that I have my husband to help and also that I have really good children.

Look, I want to tell you something. I know I said that when I don't go to meetings at school, my husband goes. Well, it's not exactly like that. He doesn't like to get involved in that sort of thing. My daughter Tania and I are the ones who go when there are meetings at Nelson's school or at Jane's school. I haven't gone to many meetings at Nelson's school because I like to go to the meetings they have during the day. I don't like to go to the meetings at night because the area there is not very safe at night.

I have to go to the dentist, but I can't. I have to take Nelson to the dentist because he needs root-canal work. I'm going to have to spend a lot of money. First, I have to take care of him and then the other children and then myself. I don't have medical insurance or anything. I went to ask if Nelson could have Medicaid or SSI, but I was told that he can get them only when he is 18. I think that these handicapped children need doctors more than normal children. They seem to need more help.

I want to teach Nelson to do things for himself because he will be able to be more independent. Then he will know how to do things without always having somebody help him. Children learn manners at home. They learn to respect their elders and their parents. School teaches you to read and write, but at home, you learn how to live with other people. Sure, schools are important, but parents are much more important. I'm not used to talking about these things. I think about them but never talk about them. Nobody ever asked me about these things, so it's hard for me to talk about them.

Introducing the Gomes Family

I met Mrs. Gomes through Mrs. Duarte, who spoke to Mrs. Gomes about my research and sent her one of my flyers. Mrs. Gomes told Mrs. Duarte that she was interested in participating and asked Mrs. Duarte to give me her telephone number. I called Mrs. Gomes a few days later, and we made arrangements to meet the following week.

I met Mrs. Gomes at her home. We discussed my research at length, and I explained the consent form to her. Her daughter Dolores was sitting nearby watching television. When she heard me tell her mother that I was interviewing parents with children in special education, Dolores became interested in the conversation and asked me questions about my research, which I answered. Mrs. Gomes agreed to participate and signed the consent form. Because she was not feeling well, we ended the initial meeting with the agreement that I would call her in a few days to make arrangements for the first interview.

When I called her a few days later, Mrs. Gomes was still not feeling well. I kept calling her every few days to see how she was feeling, and every time I talked to her, we had a long conversation about her ailments. It was two weeks before I was able to get her to commit to the first interview. I conducted the interviews at Mrs. Gomes's home and in Portuguese. There was a delay of a couple of weeks between the first and second interviews because she was either busy or not feeling well.

I found Mrs. Gomes to be very sensitive and emotional. Every time we talked, almost no matter what the subject, her eyes would fill with tears. I found myself either holding her hand or putting my arms around her.

Mrs. Gomes lives in a small row house in the heart of the Portuguese neighborhood. All her neighbors are either from Portugal or from the nearby regions of northern Spain. Mrs. Gomes's house has two storeys and a basement, and the façade is covered in vinyl or aluminum siding. The front door is reached by a low stoop. The basement formed a separate apartment that Mrs. Gomes rented out. When I first went there, Mrs. Gomes's family occupied the other two floors of the house. The front door opened on to a paneled hallway with a flight of stairs leading to the second floor. Halfway down the hallway, on the left side, was a door that led to Mrs. Gomes's living room. The living room was the front room of the house with a window that looked out onto the street.

As I entered the living room, I faced a couch against the opposite wall. To my left was another couch against the front window, and to my immediate left, a reclining chair where Dolores was sitting watching television. To my right was the dining room and beyond that the kitchen. The second floor consisted of a separate apartment where the family had their bedrooms. At the time of the second visit, the layout of the first floor had completely changed. Beds and dressers were crowded into the living room and dining room. Mrs. Gomes explained to me that they had rented out the second-floor apartment in order to make ends meet.

Mrs. Gomes has two children: Antonio, who was 22 and worked for a large company, and Dolores, who was almost 18 and a junior in high school. I did not meet Antonio because he was at work at the time of the interviews. Dolores has spina bifida. She attends a regular high school that has a special program for physically handicapped students. Dolores attends regular classes for most subjects, but goes to a resource center for extra help in English and mathematics. She attends only classes in English. Dolores also attended ESL classes when she first came to this country at the age of nine.

Dolores has a very pretty face with large, expressive eyes. She is very short, her body is a little twisted to the left, and she walks with braces. During the period of these interviews, Mrs. Gomes was struggling to get new braces for Dolores because she had outgrown her old ones and they were pinching her. Mrs. Gomes could not really afford the new braces, and Mrs. Duarte had to find a way for Mrs. Gomes to pay for them. At first, I thought that Dolores was friendly but a little quiet. After the second interview with her mother, I had a chance to talk at length to Dolores. She really opened up to me when I told her that I had been a nursery-school teacher. She told me that she really loves children and she wants to be a nursery-school teacher, too.

Dolores also told me that she was going to take driving lessons. Both she and her mother were very excited about this. I thought to myself that this would be very good for her because it would give her increased opportunities for independence and a social life of her own. Throughout it all, I noticed a sadness about Dolores. It seemed to me that deep down she was not a very happy child.

Mrs. Gomes's Story

We have been in the United States for about nine years. I came here first with Dolores when she was little to take her to specialists to see if they could help her. At that time, we went back and forth to Portugal. We decided to stay here permanently nine years ago.

What brought me here was my daughter's disability. We came to find better services for her. I found that the services, even though better than in Portugal, were not what I had expected. I think that this country has a lot of job opportunities. However, when it comes to health services, it is not as advanced as it should be. I feel that here in this country, if you have money and health insurance, you can have all the benefits, but if you don't have either of those things, you have nothing.

I worked as a nurse in Portugal for 25 years. I had a certain social position there. I had friends, good contacts, and I had my family. I consider family to be most important. Here I have nothing. I have a brother who lives here, but he doesn't have time for me. I can't even work as a nurse here because my English is limited; and although Dolores doesn't depend on me as much as she used to, when she was little, she still depends on me. My life here is empty. I don't blame the United States for my not having a good life. After all, I wasn't forced to come here. I came here because I wanted to. I came here because it is better here for my daughter. For example, when it comes to her leg braces, there's no doubt about it. The braces here are much more sturdy, and they last longer than the ones made in Portugal. In my opinion, this country is good only for the lazy, the thieves, and those who don't want to work. Those people have everything. They get everything from the government. However, if you do work and you don't have health insurance, you are not entitled to anything. I am expressing my feelings because this is a free country and I am a free person and I have the right to express my feelings.

Finding out that Dolores was handicapped was a big shock to me. All I could do was cry. I called several specialists that I knew. One of them was my godfather, who was a doctor. He suggested that the baby be moved to another hospital where she could have a spine operation. However, there was one doctor that told him that the baby should not be moved anywhere because she was not going to live very long.

Then I talked to another doctor who told me that if it had been his child, he would send her to the other hospital to have the operation. I listened to him because he was not only a doctor, but he was also a father and he was Catholic. Those factors were important to me, so I had my child operated on when she was two days old at the other hospital. The hardest part for me was that I was in one hospital and my child was in another and I couldn't be with her. I think that being a nurse really helped me when I was finally at home with Dolores because I knew how to take care of her. I don't think that I would have known what to do otherwise.

When we moved to this neighborhood and bought this house, Dolores attended the public school down the street. There they told me it was better for her to go to a special-education school. I talked to this person and that person until I found a psychologist and a social worker who were very helpful to me in finding a school.

Dolores has physical problems. That's all. I don't believe that she should be in special education. When she was in

Portugal, she went to a regular school. But if she is not in special education, she is not entitled to services for the handicapped. It seems to me that they think Dolores should be in special education because they think that there is something wrong with her mind. That's not true. Dolores is normal. There is nothing wrong with her mind.

I think that the school Dolores attends is a poor school, and it doesn't have a lot of resources. It seems to me that just because this is a Portuguese community, anything goes, and we don't deserve any better. Before I moved to this community, I lived in a community where there were just Americans. The schools were great. There were more schools, fewer students,and the classes were not so big.

When she was younger, Dolores loved to ride her bicycle. When she got older, however, she stopped riding her bicycle because of her disability and became less active. Dolores is not a very outgoing person. She feels comfortable only in certain environments. She is very affectionate, but sometimes a little aggressive, and she loves to tell jokes. She never brings any homework from school. She never has anything to do. All she likes to do is sit on the stoop and watch people go by. Dolores also loves classical music. She doesn't really like rock music. She loves children. As a matter of fact, she said that she wants to be a kindergarten teacher. I told her that if she wants to be a teacher, she has to study and get good grades so she can go to college. I don't really know what she will do. We just have to wait and see. She also loves to talk on the phone to her cousin who is in college out of town. This makes our phone bill very high. Dolores loves to check the mail to see if there is anything for her. The problem with Dolores is that she has trouble initiating anything. I always have to tell her what to do.

I think that she has friends at school, but I really don't know. It seems that it is somewhat difficult for normal children to be friends with a handicapped child. I don't think that Dolores likes to be the way she is. There was a girl down the street who was very close to Dolores when they were both little. When they both got older, the girl decided that she had other interests, and she doesn't even speak to Dolores anymore. She will walk by Dolores and pretend that she doesn't see her. It seems that the Portuguese people here are very ignorant about these things.

Antonio loves his sister. He will do anything for her. To my husband, Dolores doesn't have a disability. To him, she is just perfect. My husband is a very good father. He loves his children. Dolores is everything to me. She is like a sister and a best friend to me. As a mother, I suffer because of her problem. However, I am very happy with my daughter. I wanted God to give me a daughter, and He did. I asked Him not to take her away when we found out that she had problems, and He didn't. Dolores's handicap didn't destroy me. I live my life for her. I'm always hoping that she will get better. I'm always struggling and fighting for her. I am here to help her. I want Dolores to have a good life and to be as independent as possible.

I believe that love is the most important thing you can have. We all need love. Love is everything. Dolores is a gift from God. She is a blessing. God gave her to me because He knew that I was the right person to take care of her. I have learned a lot from Dolores. I learned to be more patient with others. I also learned to understand and to love others. When we have a handicapped child, we become soft-hearted.

Introducing the Davila Family

I also met Mrs. Davila through Mrs. Duarte. During my last interview with Mrs. Duarte, she suddenly remembered that she had someone working for her, Mr. Davila, who had a child in special education. Mrs. Duarte called Mr. Davila while I was with her and told him about my research. We then walked down to where he was working, and Mrs. Duarte introduced me to him. I showed him one of my flyers and told him about the consent form. He expressed an interest in my research and then and there called his wife to tell her about me. Mrs. Davila also expressed an interest in the research and told her husband to give me their home phone number so I could be in touch with her. I called Mrs. Davila that same evening, and we made arrangements to meet the following week. The day of the preliminary meeting I went to Mrs. Davila's house but did not find her home. I called her again that evening, and we made arrangements to meet a few days later. This time she was looking out the window for me, and I found her without any trouble. During this first meeting, we discussed my research in greater detail. She agreed to participate and signed the consent form. We agreed to meet the following week at her home for the first interview. The interviews were conducted in Portuguese.

Mrs. Davila lives just outside the community with the main Portuguese population. When I interviewed her, she was renting the first-floor apartment in a two-storey, detached row house. There was a high stoop leading to the front door of the house. By the door, there were two bells, one for each apartment. Mrs. Davila's landlord lived in the apartment on the second floor of the house. The front door opened onto a hallway with stairs leading to the second-floor apartment. To the right, as one enters the hallway, was the door to Mrs. Davila's apartment. This door opened onto the living room. To the right was a couch against the two windows at the front of the house. Straight ahead was another couch against the window at the side of the house. Against the left wall was a television set. Also in the room was Sonia's wheelchair. To the far left at the back of the room was a folding door, which I assumed led to the dining room. This door remained closed during our interviews. Compared to most of the houses I visited, Mrs. Davila's was very sparsely furnished.

Mrs. Davila has four children. Paula, the oldest, was 22 and at a university in Portugal. Mrs. Davila's other children were triplets: Emilio, Katia, and Sonia. They were three years old at the time of the interviews. Sonia has cerebral palsy and attends a cerebral-palsy center. Emilio and Katia are in a full day program at a day-care center. Emilio, although not in special education, does wear braces at night to strengthen his legs.

I met two of Mrs. Davila's children: Sonia and Katia. During the first interview, Katia was there because she was home from school with a cold. I played with her for a few minutes, and she seemed to be a perfectly normal three-year-old, although a little small for her age. I met Sonia during the third interview. Sonia's left side seemed to be much more affected by her cerebral palsy than the right side. Her head was tilted to the left, and her left arm was bent with her hand closed in a fist. She could not walk, but crawled everywhere with great enthusiasm. I have rarely seen a happier child. She often smiled and threw kisses. She also showed a great desire to do things on her own and the determination to overcome great obstacles. Sonia does not have much speech, but she can understand and respond in both English and Portuguese.

I found Mrs. Davila to be open and very willing to talk. She told me that this had not always been the case. She said that for some time after the triplets were born, she had had a great deal of trouble expressing her feelings about Sonia's condition.

Mrs. Davila's Story

We have been in the United States for two years now. What brought me here was Sonia's disability. I came to seek help for her. The doctors in Portugal told me that it would be better for me to come here because there was nothing more they could do for her there. They told me that Sonia would never be able to walk or talk or even eat by herself. They said that Sonia had cerebral palsy, and they didn't understand what that was, so they couldn't do very much for her.

I noticed that Sonia had a great desire to get better, so I had to come here to get help for her. I came first with the triplets and stayed for two months. During those two months, I took Sonia to several doctors and therapists, and she went through a lot of tests. At the end of the two months, I returned to Portugal, and my husband and I decided to sell everything and come here to live. We sold our house, our cars--we sold everything to come here.

I have accepted that Sonia may never walk, but my husband has not. He believes that she will walk one day. All I want is for Sonia to have the best life that she can have. I want her to be as independent as possible because when we get old, we won't have the strength that we once had, so it will be very difficult to take care of a handicapped child. However, I will go to the end of the earth to help her.

My life in Portugal was a very good life. Here I don't have a life. My husband and I had very good jobs in Portugal.

We had our house, our cars, and we were financially comfortable. Here we have nothing. Everything we have was given to us by friends and neighbors. My husband has a reasonable income; but, you know, it is very difficult with three babies. Also, it takes a lot of money to get things for Sonia. Our life here is very different. There was a time when we didn't even have money to buy food. My life has changed completely. One day my life was like a spring day filled with flowers. The next day it was as if there were an earthquake and everything turned upside down. It was very difficult, not just for me, but for my husband as well. At least he has his job, and he is always with people. I, on the other hand, don't have anything or anyone. I have stopped being the happy person that I once was. Now I'm a very sad and unhappy person. I'm not me. I'm just a shadow of my former self. When I found out that Sonia had a disability, it was a shock to me. All I could do was cry. I stopped living for me. Now I live for her and for the others.

I thank God that my husband and I have a strong relationship. If it weren't for that, I don't know what we would have done. I don't know how we would have gone through this. We have been together for many years, and we have a deep respect for each other. My family, especially my mother, was very supportive. She was always there for me, and so were my friends. I don't have them here, but at least I have my husband, and he has been wonderful. I also have my grown daughter Paula, who lives in Portugal. She is a wonderful daughter. She has never given me any trouble. We are very close. When she was little, she used to tell me everything that went on in her life. As a matter of fact, she still likes to talk to me, and I also like to talk to her.

Sonia was normal when she was born. She was just as normal as the other two children. They had to be put in an incubator because they weighed only about two pounds each. They stayed there for about seven days. I think that Katia stayed a little longer because she was somewhat smaller than the others. I believe that what happened was that the doctors turned off Sonia's incubator too soon. She should have had more time. When they turned it off, she couldn't get the oxygen that she still needed and she had a hemorrhage to her left side. Thank God that it affected only her motor functions and not her brain. As a matter of fact, the doctors here say that Sonia is a very bright child. What upsets me to no end is knowing that a doctor and a human being did this to my child. He robbed Sonia of her childhood and her life. While the other children are running and playing, Sonia is doing therapy or going to doctors. If Sonia had been born handicapped, I think that I could have accepted it. But when I think that a human being did this to her--that I can't accept.

When we first came to this country, Sonia was a mess. Her arms were going every which way. If she turned her head to the right, her arm would turn to the left. It was horrible. She is doing much better now. She is moving her arms much better. She is starting to pick up the toys that we put on the floor, and she wants to do everything by herself. Of course, she can't, but she tries. When she was a baby, she wasn't interested in anything, but now she is interested in everything around her. She wants to do what the other children are doing. She wants to eat by herself, and she has expressed a desire to walk. She is always asking us to help her stand up so she can try walking. It is really sad. Sometimes I feel so sorry for her, not because she has a handicap, but because she can't do the things that she wants so much to do.

Sonia is a happy child. She is always smiling. Everyone likes her, and she likes everyone. She is always sending kisses to people. She also loves going to swim class. We take her every Saturday. She even loves doing all the therapies and has tremendous will power. Sonia loves going to school and attends a cerebral-palsy center. I'm very happy with the school. She is learning a lot there. Sonia also has a private therapist twice a week. I have learned to do the therapies, and I do them with her every night before she goes to bed. When we do therapy here, everyone gets involved. Emilio and Katia do them on each other and on their dolls. Emilio and Katia love Sonia. I think that, for them, Sonia is a little baby to play with because she can't walk and is still in diapers. They are also very protective of her. They are always there to make sure that nothing bad will happen to her.

We were very lucky when we came here. We met a woman who helped us with everything. She wrote letters to organizations, called the churches to say a Mass for Sonia so we could raise money for her, and also helped us find the right school for Sonia. She got the Boy Scouts to pay for Sonia's wheelchair and also for Sonia to have a bank account just for her expenses. They are the ones who are helping us now. We have been very lucky. Everyone has been very helpful to us.

Introducing the Tavares Family

Mr. Elias of the board of education gave me Mrs. Tavares's name. He thought she would be able to help me find participants because she was a special-education teacher. I called Mrs. Tavares, introduced myself, and explained my research. During the course of this conversation, Mrs. Tavares said, quite matter-of-factly, that she was also the parent of a special-needs child. She was interested in helping me for a number of reasons: She was Portuguese, had a special-needs child, was a special-education teacher, and Mr. Elias had asked her to give me a hand. We made arrangements for a preliminary meeting a few days later at her office.

At this meeting, we talked about my research in detail, and she signed the consent form right away. After that, she took me around the office, introduced me to her coworkers, and gave them copies of my flyers. Mrs. Tavares said that although she was eager to participate, she could not do it right away because she was swamped with work. She told me to give her a call at the beginning of the school year to arrange a time for the interviews. At the beginning of the school year, I called Mrs. Tavares, but we kept missing each other for several weeks. Then one day I called her at the office, and she happened to pick up her phone, which was unusual because she was almost always out in the field. We made arrangements to meet at her home a few days later for the first interview. The interviews were conducted in English.

Mrs. Tavares lives in the center of the main Portuguese community. In fact, she lives within walking distance of several of the other participants and knows one of them socially. She and her family live on the first floor of a two-storey row house that she and her husband own, and they rent the second-floor apartment. One enters the house by climbing a low stoop. The front door opens onto a long hallway with a flight of stairs leading to the second floor. The door to Mrs. Tavares's apartment is at the far end of the hallway. The living room was paneled, with a couch to the right along the wall, and across from the couch was a console with a china closet. Behind the living room was a large kitchen with a dining table. Next to the console was a door leading to a small study, and to the left of the front door was a door that led to the bedrooms, which occupied the front of the house.

Mrs. Tavares has two children: Nina, who was 16 months old, and Bruno, who was four. Bruno is a special-needs child.

He is the only survivor of triplets who were born four months premature. Bruno is totally blind and has many developmental problems because of his prematurity and the long time he had to spend in the hospital. He attends a special preschool handicapped program at a private school. The school has students with various handicaps.

I found it very easy to talk to Mrs. Tavares because I had so much in common both with her and with Bruno. We had both come to the United States at a young age and had been educated in this country; we also are professionals in special education. When she talked about Bruno's blindness and her experiences with his school, I could relate to it in a special way because of my own sight problems and school experience. I could remember what my own mother had gone through in trying to get services for me.

I found Bruno to be an active and happy four-year-old. He seemed to be of average size for his age and quite robust, especially considering his many physical problems. He had trouble taking food by mouth and had to be fed by a tube that had been surgically implanted. Bruno's speech was very clear in both English and Portuguese. He seemed to be completely bilingual. I noted, however, that his speech patterns seemed more like those of a two-year-old. For instance, when I observed him, he usually spoke in two-word phrases and usually referred to himself by name, making statements like "Bruno wants."

I had some time to spend with Bruno and his sister Nina before and after each interview. I observed that while Bruno can walk, every time he came over to me, he came on all fours and appeared able to negotiate obstacles more easily by crawling. Nina seemed to know that there was something different about Bruno. Mrs. Tavares told me that Nina had already figured out that Bruno cannot see.

Mrs. Tavares's Story

I came from Portugal to the United States when I was about five or six years old. My parents were farmers in Portugal, and they wanted to better their live and their children's lives, so we came to this country. My dad had only the equivalent of a third-grade education, and my mom was illiterate.

I have one brother and one sister, both older than I. When we were in grammar school and high school, we were able to teach my mother how to sign her name, but that's as far as she got. My mom has some knowledge of the English language, but not enough to be able to carry on a conversation with you.

I was in school in Portugal for only two or three months. I really don't remember very much. I do remember, though, that we had the typical one-room school where the teacher taught different grades. When I first came from Portugal, I knew nothing of English. The first two to three years were very difficult. I can still remember that as if it were today. The teacher that I had did not speak Portuguese. Fortunately, there was one kid in my class who had come from Portugal about one year before I did, and she already knew some English terms, so she was able to help me.

When I went to high school, there was only one bilingual teacher. As a matter of fact, she was from my hometown and is now a principal at another school. I went to elementary school, high school, and college in this city. Although neither one of my parents has an education background, their main focus for coming here was a better life for us. They used to say to us, "We will work, but your main priority is to go to school." They would work two or three jobs, but we had to go to school.

I love Portugal. It's my home, and I will always love it. I used to go to Portugal all the time when I was single. Now that I'm married, well, the finances don't stretch out that much. With two children, my salary, and my husband still in school, it is financially draining on us. We have been married for five years. Since we got married, we purchased this house and we have the two children. Let's face it, it is my income that supports us. We are trying to see if we can go to Portugal next summer. It would be our first vacation since we have been married. We are really looking forward to it, and we are trying to save every little penny.

I became pregnant soon after I got married. When I went to the doctor in my third trimester, she told me that I was carrying triplets. There were no multiple births in my family as far as I know, but multiple births were very prevalent in my mother-in-law's side of the family. Bruno was one of the triplets. The other two didn't survive. After a couple of weeks, the doctors told us to be on the lookout for complications because of the prematurity and because Bruno was on oxygen for such a long time. When we were told that Bruno was going to be blind, I couldn't accept it. It was all very difficult to understand, and I rebelled. I rebelled against God and everything else that I believed in. It was very hard on my husband and me. I think that it made our marriage a lot stronger, too. We were able to live through it and go through all the pain together.

Bruno was a fighter from day one. He was hospitalized for the first 16 months of his life and was in the intensive-care unit for eleven and one half months. When he came home, he was functioning at a week-old level. He is fine now, but he was and is very orally and tactile defensive. Any time that someone went to put something in his mouth, it was to put tubes in it. He can't see, and he didn't know what was going on in his mouth, so he became very defensive. When someone had to hold his hand, it was to restrain him to stick a needle in him. So he built up these defense mechanisms. He is now beginning to emerge by letting us do hand-over-hand. Usually, if we don't give Bruno any previous command like "Let mommy give you a hug," and just grab him, he gets very scared. We always have to cue him on what we are going to do. I hope that in time these things will correct themselves, but for now it is understandable. If I couldn't see and someone were always putting something down my throat and always grabbing me, I would get scared, too.

Bruno is not yet toilet-trained and he is almost five years old. He was almost toilet-trained last year, but I don't know if he got scared of the potty or what. I know that something must have happened. I guess I will never find out why he doesn't want to go on the potty. The teachers are working with him now.

Bruno is a very bright little boy. Anything he knows in English he is able to translate for you to Portuguese. He can ask me for things in English and Portuguese. Bruno needs a lot of reinforcements, and he needs a lot of the one-on-one activities that they do in school so that he can get ready to do the things that he scatters in.

Bruno is truly what I call a miracle baby. His chances of survival were less than five percent. He has come a long way. Now he is just like any four-year-old. He is at that stage where it is his way or no way. If anyone had told me four years ago that Bruno would be where he is now, I would have told them that they were crazy. I used to ask the doctors if Bruno was going to talk or if he was going to walk. They just told me that we had to wait until he reached that milestone.

People seem to think that it is easier to cope with having a special-needs child when you are an educator in special education. Well, it is not so easy. You have to go through the hardships. I have accepted that Bruno is blind, but I have not given up on the fact that someday something may be done for him. Thank God his condition is stable and he is not getting any worse. I'm not saying that I would love for him to have my vision, but I would like him to have some usable vision. If he has the intelligence, he can succeed whether he is blind or not, and that is the important thing.

My daughter Nina is at the age now that Bruno was when he came home. When I was expecting Nina, I was really scared that something would happen to her. I prayed to God all the time. I think that I finally enjoyed my pregnancy when I was in my seventh month. At that time, I realized that everything was going to be okay. It was a very trying and draining time for me.

Bruno appears to be musically gifted, and if he really is, I will try my best to encourage him. He has both individual music therapy and group music therapy at school. He comes home very excited when he has music at school. He will sit at his little piano and play "Twinkle Twinkle Little Star" and "Happy Birthday." He can play a variety of little songs by ear. No one has ever taught him. He does it all by himself.

For his age and considering the handicaps that he has, I think that Bruno has a nice social life. He has a little circle of friends--five or six friends whom he plays with. He knows them and they know him, and they know about his handicap and how to deal with him. That's what I find a little difficult at times. Children sometimes don't understand why Bruno can't see or that he can't do this or that.

My husband is talking about going back to Portugal one day. I have never really lived in Portugal. I have gone there only for vacations. I would love to try to live in Portugal, but with the understanding that if it doesn't work out, we will come back here.

CHAPTER V

THE FAMILIES AND THEIR CHILDREN WITH SPECIAL NEEDS: THE BEGINNING TRANSFORMATION

This chapter and the one that follows are devoted to a presentation of the findings according to the categories that emerged during the final analysis of the data. My initial and major focus for the present research project was on the participants' attitudes toward parent involvement in the education of their children with special needs. However, the participants themselves talked at some length regarding their relationships with the children and how they and the families dealt with these children's special needs. That topic is the subject of this chapter. In Chapter VI, I shall present findings on the parents' experiences with the school system, the attitudes of these parents toward parental involvement, and their comments on how they want to be involved in their children's education. At the end of each of these chapters, there will be a thematic discussion of findings.

As was the case in the previous chapter, in these chapters also the analyses are supported by quotations from interview transcripts that, except in the cases of Mrs. Tavares and Mrs. Castelo, have been translated from the Portuguese and edited to avoid digression and repetition.

Learning for the First Time about Children's Disabilities

One of the most emotional parts of every interview was the parents' account of the occasion when they realized that their child was not like other children. The emotional quality of my conversation with Mrs. Gomes when she told me about Dolores was typical of conversations with most of the other mothers. As Mrs. Gomes recounted her experience, her eyes filled with tears. She turned and stared out of the window and seemed to be very upset. I could feel her discomfort and told her that we could go on to another topic if this one was too upsetting for her, but she said that she did not want to change the subject, she wanted to tell me the story of her experience. Mrs. Gomes then began by telling me that Dolores had been delivered by a midwife in Portugal, and she went on to say:

> I could tell there was something wrong with her as soon as she was born. The midwife didn't say anything, but she kept calling other nurses and doctors to come and see the baby. I got out of bed and I went to see my baby. It was then that I realized there was something wrong. Dolores has spina bifida myelomeningocele. Finding out that Dolores was handicapped was a big shock to me. All I could do was cry. But it didn't destroy me because I started to live my life for her.

Sadness seemed to overwhelm her as she spoke. But she forged ahead, determined to tell her story.

Mrs. Dias and I met in a coffee shop for our first interview. When I asked her to tell me about her child with special needs, she became very silent, started fidgeting with the cup and saucer in front of her, and gazed alternately out of the window and down at the table. She explained that it was not that she did not want to answer. It was just that she had to collect her thoughts and find the right words to express herself because it had happened a long time ago and no one had ever asked her to talk about it before. Then she continued:

> I didn't notice anything wrong with Nelson when he was born, but I think that my husband noticed something wrong with the baby and never said anything. Sometimes I'd see him looking over in the crib but never saying anything. Then one day when the boy was 21 days old, his doctor called and told me I had an appointment to take Nelson to see her the next day. When there, the doctor kept asking me, "How is the baby? Do you think that he is developing okay?" I told her he was. My oldest daughter was almost two years old, and all I saw was that Nelson was a little slow, which didn't worry me. The doctor continued to ask me, "Are you sure that there's nothing wrong with him?" When she said that, I became suspicious but didn't say anything. My husband started to cry. The doctor looked at me and said, "I have something to tell you. Your baby Nelson is not a normal child. He is not developing normally. Do you know why? It's because he has Down syndrome." I started to cry!
>
> The doctor then explained everything to me about the illness. I was stunned; I couldn't even talk. It was a shock to me, and my husband continued to cry.

Mrs. Dias's husband told her that he and the doctor had known all along that Nelson was handicapped:

> My husband said later: "Yeah, I knew, but the doctor didn't want me to tell you because she wanted you to see for yourself that Nelson wasn't normal. But you didn't, so we had to tell you." After that, I noticed that Nelson was different. He was always getting sick.

In contrast with Mrs. Dias, Mrs. Davila had noticed right away that something was wrong with Sonia. Sonia was one of triplets and had been born in Portugal, and she had noticed something different about her while the babies were still in incubators.

On the day of our first interview, Katia, one of the other triplets, was home from school sick. When I asked Mrs. Davila to tell me about Sonia and her special needs, she became very silent. She started playing and talking to Katia, who was sitting on her lap. I waited for a bit and also started to talk to Katia. At that point, Mrs. Davila told me that she had to think about how she was going to talk about noticing that her child was different. Finally, she said:

> I was the one who noticed that there was something wrong with Sonia. She seemed to be a very still baby, and she just slept and slept. I told the doctors that there was something wrong, but they just ignored me.
>
> When Sonia was seven days old, the doctors examined her and told me that she had had a hemorrhage to her left side, but that she was going to be all right. I tried to believe them, but I wasn't convinced. I think they knew that there was something wrong, but they didn't want to tell me. When Sonia came home, I noticed that her arms and legs were stiff, and she didn't seem to be interested in anything.

During those first three months, Mrs. Davila had gone back to her doctor, and then from one doctor to another, trying to tell them that something was wrong with Sonia. She finally found one who would listen to her and ordered a series of tests and X-rays. When the results of these tests and X-rays came back, they indicated that Sonia had cerebral palsy.

> When I found out that Sonia had a disability, it was a shock to me. All I could do was cry. It was such a shock that I couldn't even talk about it. As soon as I found out about Sonia's disability, I stopped living for myself and started living for her and the other babies.

Mrs. Davila said she had been very depressed for a long time and had not wanted to talk to anyone about Sonia's problem, but now she felt that she could open up to me. As she related her story, she seemed almost palpably angry. She told me she was angry because she felt that no one had listened to her. She felt that the doctors just kept putting her off.

Mrs. Paiva found out that something was wrong with her child shortly after the child's birth. When Elia was born, she was a full-term baby, but she weighed only four pounds and five ounces. This was under the five pounds required for discharge from the hospital. During the first ten days, while the baby was still in the hospital, the doctors noticed that her head was too big for her body. She went on to say:

> Elia was transferred to another hospital where they examined her and told me that one side of her brain had not developed and was very dry. That's her problem. They call it "missing brain," and because of that, they told me that she wasn't going to live very long. It was a shock to me because I thought I was going to lose her. Time went by, however, and she started to get better. She was developing, and I felt better.

Of all the participants, Mrs. Tavares was the only one who had had some indication that there might be a problem with her child because he was so premature. Her son Bruno was the only survivor of triplets who were born four months' premature in the United States. Doctors told Mrs. Tavares to be on the lookout for complications because Bruno was so premature and had developmental delays. They were also concerned because Bruno had been on oxygen for a long time.

> They told us that Bruno could have one, two, or three of the "three evils," as they called it. The first "evil" was hemorrhaging, which caused mental retardation. The second was intestinal deterioration, that is, when the intestines are literally blocked. The third "evil" was blindness.

> The possibility that Bruno could get one, two, or all three of these "evils" was very strong because he was so premature.

Bruno was approximately four months old when he was examined by a neonatologist, who noticed that he had detached retinas. His parents were told that he would be blind. Mrs. Tavares continued:

> I think that no matter how educated you are, you are completely illiterate to what the doctors are telling you. I guess I was in a state of shock and disbelief. Thank God that my cousin was a doctor, and she was able to explain everything to me. Otherwise, I don't know what I would have done.

When Mrs. Tavares told me about Bruno, she, like Mrs. Paiva, did not display great emotion. Her manner was, however, not as matter-of-fact as Mrs. Paiva's had been.

The doctors in Portugal told Mr. and Mrs. Xavier as soon as Jorge was born that he had Down syndrome. Mrs. Xavier told me that they were shocked when they heard the news, but that their strong religious faith enabled them to accept and cope with their child's handicap.

Both Mrs. Carvalho and Mrs. Duarte, whose children were born in the United States, themselves realized during the first few months of their children's lives that there was something unusual about the way the children were developing. Mrs. Carvalho mentioned that she kept telling her doctor that she did not think that Quim was developing normally. The doctor, however, told her that Quim was just careless and lazy and there was nothing wrong with him. After some time, Mrs. Carvalho's sister took them to see another doctor, who immediately diagnosed

Quim as having cerebral palsy. Mrs. Carvalho's initial reaction to being told that her child was handicapped was that she felt that life was already very difficult and it was a misfortune to have a child like this.

Mrs. Duarte told her pediatrician on several occasions that Carlos was developing differently from the way his siblings had. She claimed that the doctor took no notice of what she was telling her and kept saying that there was nothing wrong with Carlos. Finally, Mrs. Duarte took Carlos to another doctor who was a neurologist. It was not until Carlos was five years old that this same neurologist told Mrs. Duarte that something was definitely wrong with Carlos and that he probably had Down syndrome. Unlike Mrs. Carvalho, Mrs. Duarte told me that she had never felt bad about having a handicapped child, although it had been difficult in the beginning. She also recalled that it had been much harder for her husband to accept that Carlos was handicapped because there were two other cases of retardation in his family.

The participants cited above realized that there was something "different" about their children at birth or shortly thereafter. Mrs. Castelo, however, whose children were born in the United States, did not become concerned that her twins might not be developing normally until after the birth of their younger sister. She went on to tell me:

> My little one was 13 months old and she was starting to sound out words; and my two boys, who were already two and one half years old, weren't saying anything. I took them to the pediatrician, and I told her about it. She told me

> that because they are boys and because boys are lazier, I should give them more time.
>
> When I told the doctor again that my little one was already talking, she then told me to look into a child development center. They just did a hearing test. Everything seemed to be okay with the hearing. Then I was referred to a hospital, and they told me that they were both autistic. I didn't know what autism was. I was told that it was a developmental disorder.
>
> At first, I blamed myself for them being autistic. Autism is hard. It is difficult to cope with and to grasp. I didn't even know that it existed. It hit me like a time bomb.

I conducted the interviews with Mrs. Castelo in the teacher's lounge at the school where she worked. Although we were alone in the room, as she started to tell me about her twins, Mrs. Castelo lowered her voice and looked around as if she did not want anyone to hear what she was telling me. She said that she did not mind talking about the boys and their condition, but she did not want any strangers to hear what we were talking about. Mrs. Castelo seemed almost neutral in affect as she spoke. She did say, however, how difficult it was for her to have not one, but two special-needs children.

Children with Special Needs in Their Families

These special-needs children do not live in a vacuum. They live in families, and their parents need to meet the many special needs that some of the children have in the context of the other demands of family life. All but one of these children have siblings with whom they interact. The deep love and devotion these parents showed for their children and the concerns and hopes for their future are woven throughout the interview data. These topics are discussed in this section.

Meeting the "Special" Needs of These Children

Mrs. Tavares mentioned again that when Bruno first came home from the hospital, he was already one year old but was functioning at the level of a week-old infant. She explained that although Bruno was four years old and seemed to be making improvement developmentally, he was and still is at the time of this writing very defensive, both orally and tactilely. She added that Bruno's defensiveness was due to his having been poked and prodded so much during his year in the hospital.

When I first met Bruno, I called him to come to me, which he did. I then tried to hug him and was surprised at his reaction. As I touched him, he immediately stiffened and started to move away from me. It was not until Mrs. Tavares explained Bruno's defense mechanisms that I understood why he had reacted the way he did. Mrs. Tavares also told me that she had to give Bruno a ventilating treatment twice a day. This treatment was to expand Bruno's bronchi to help him breathe better. Bruno was fed by means of an implanted tube twice a day at home and by mouth once a day at school. Because of Bruno's blindness, most of his toys had to make some kind of sound so he could locate them easily.

Beyond the care that most three-year-olds require, Mrs. Davila had to take Sonia to her physical therapists at least twice a week. She not only had to learn from these therapists how to work with Sonia at home, but also had to learn special techniques for performing "simple" tasks such as holding, carrying, and bathing her daughter.

Mrs. Castelo told me that she had to struggle every day to communicate with her son Benito, who is autistic, and to have him communicate with her in order to draw him out of himself:

> I want Benito to talk to me. Sometimes I get frustrated with him. . . . It is frustrating not just for me, but for him, too, because he wants to say something but he can't.

She went on to explain that she felt it was important to take Benito out so that he would be exposed to the world around him. Benito also needed more help getting ready for school than a "normal" seven-year-old, and Mrs. Castelo sometimes found herself doing everything for him so that he did not miss the school bus.

As these children get older, their needs may change, but they still usually require more care than other children. For example, Mr. Xavier told me that he was the one who shaved his 15-year-old son Jorge and that he was the one who, at the time of the study, had to take Jorge to school because he had refused to ride the school bus. Mr. Xavier also explained the seeming dichotomy for many of these parents between encouraging the children to be independent and the need to do everything for them because of time constraint:

> We are trying to teach him to do everything for himself. We don't do things for him because children with Down syndrome are very lazy. . . . They have a tendency to get fat and be lazy. We have a tendency to help him. We help

> him get dressed in the morning. He can do it alone, but because we don't have much time in the morning, I end up doing it for him.

As with Mrs. Castelo, Mr. Xavier told me that he, too, wanted to expose his son to everything. He took Jorge everywhere with him, not just to expose him to everything, but also for him to walk for exercise. Like Mr. Xavier's son Jorge, Mrs. Gomes's daughter was also a teenager at the time of the study. Even though Dolores appeared to be quite independent in many aspects, Mrs. Gomes indicated that her daughter was still somewhat dependent on her:

> Dolores still depends on me quite a bit--not as much as she did when she was little, but she still depends on me. I still have to give her my arm when she goes down the stairs, and I have to help her bathe and wash her hair. She still can't do a lot of things by herself.

Mrs. Paiva, whose daughter Elia was 21 years old at the time of the study, told me that she still had to do everything for Elia. She went on to say:

> When I take Elia to the bathroom, for example, I have to clean her. I have to brush her teeth, bathe her, brush her hair, and also get her ready for school. I have to do everything for her because she can't do anything by herself.

Mrs. Paiva had also learned exercises to help strengthen Elia's muscles from Elia's physical therapist and did them with Elia every day. Because Elia did not like wearing her glasses, Mrs. Paiva had to make sure that Elia wore them so as not to strain her eyes. As with many of the participants in this study, Mrs. Paiva, too, took Elia out with her whenever possible.

Although these children have different handicapping conditions, there appears to be a good deal of similarity in the way these parents try to meet their children's special needs. When talking about her son Nelson, Mrs. Dias emphasized that she encouraged her son to speak by talking to him and also asking him questions. She went on to tell me that at the time of the study, she needed medical care but had to postpone it because Nelson also needed medical care at the same time and she felt that Nelson came first. Her comment seemed to touch a common thread among these parents when they spoke about meeting their children's needs: "First, I have to take care of him, then the other children, and then myself."

For many of these parents, meeting their special-needs children's "special" needs includes involving these children in the world around them. Mrs. Carvalho, whose son Quim was 22 years old at the time of the study, made it a point that Quim participate in all the community groups and activities with which she was involved. Mrs. Duarte, whose son Carlos was 21 at the time of the study, also felt that it was important to make Carlos a part of the world around him. Not only did he go along whenever the family went out to community functions together, but he was also given responsible jobs in the family business.

Relationships with Siblings

The most striking feature of these special-needs children's relationship with their siblings was how "normal" it was. These parents reported that their other children loved the child with special needs. In a few instances, the parents also reported a bit of sibling rivalry, as one would expect to find in any family. According to these parents, some of the other children seemed to be envious of the extra attention that the special-needs child received. In general, however, many of the parents told me that their other children felt very protective toward the special-needs children in the family. All but one of the special-needs children in this study had siblings. The exception was Mr. Xavier's son Jorge, who was an only child.

Both Mrs. Dias and Mrs. Davila also described relationships among their children that could be found without difficulty in any family. Mrs. Dias told me that Tania, her oldest child, and Nelson, her middle child and also the child with special needs, were very close and did everything together. Mrs. Dias also told me that her youngest child Jane was not very close to Nelson and that Jane seemed to be a bit envious of Nelson because she felt that the family babied Nelson too much.

According to Mrs. Davila, her two other triplets, Emilio and Katia, seemed to feel that Sonia was a baby for them to play with because Sonia could not walk and still wore diapers. Katia loved to talk to Sonia but sometimes felt a little envious because she thought that Sonia received more attention than she did. Mrs. Davila went on to say that Emilio and Katia loved Sonia and loved being with her, and they were always there to make sure that nothing bad happened to Sonia.

Mrs. Tavares explained to me that because of her son Bruno's developmental delays, he needed the same constant attention as his 16-month-old sister Nina. It often seemed to her that it was almost like having twins because she had to do everything for both children. She went on to say that from an early age, Nina could tell that there was something different about her brother Bruno:

> Nina picked up on the fact that Bruno is blind, and she would go and steal his toys and then would crawl away from him. She knew that Bruno couldn't see her, but what she has not yet figured out, though, is that if she plays with the toys, since most of them are sound oriented, Bruno can locate them in two minutes. When he finds her, she has this surprised look on her face, like how did he find me? She has recognized that Bruno cannot see.

Mrs. Tavares also said that she noticed that Bruno's handicap also affected the way the children played together:

> Because Bruno is blind, he doesn't recognize his own strength. He is harsh sometimes. He will knock her down and he will hurt her without meaning to. She won't really cry, but she will start complaining. There are certain things that she has picked up on, but they are good friends. He won't bother her, but she knows that she has to play with him in a different way.

Mrs. Castelo also explained that Benito's handicap influenced the way that his siblings played with him. Her other children liked to play with Benito, but he seemed to prefer to stay in his own world:

> The kids like to play with him, but he doesn't want to play with them. He just likes to stay in his own little world. He used to be worse than he is now. In the past, he would go to a corner and stay there, but now he comes in for toys and stuff.

Mrs. Carvalho related that when her younger son Silvio was little, he could not fully comprehend that Quim had a handicap and was constantly asking his mother why Quim was the way he was. When Silvio got older, he came to understand his brother's disability: "Silvio is a very good friend to Quim, and he loves him very much." This theme was echoed by the other parents whose special-needs children had adult siblings. Mrs. Paiva, for example, indicated that her other children loved their handicapped sister Elia, and they were very good to her; her sons liked buying things for Elia. Her older daughter, who lived in another state, enjoyed spending time with Elia when she came to visit, and her grandson loved Elia. She pointed out that they played together a lot because he was seven years old at the time of the study and Elia had a mental age of eight.

Mrs. Gomes also spoke of the close relationship between her children:

> Dolores's brother Antonio is crazy about her. He loves her very much. If anyone does anything to hurt Dolores, he goes crazy. He will do anything for her. He also likes to take her everywhere with him.

Mrs. Duarte mentioned that Carlos and his brother and sister were very good friends. She also talked about the effect that Carlos has had on his siblings and how much he loved them:

> I think that Carlos has encouraged his brother and sister to do the most they can do with their lives. Carlos loves his siblings very much. As a matter of fact, when he was little, he made a lot of things in art class for them. When my daughter got married, Carlos read a prayer from a book. He said that he wanted to do it for his sister and that he wanted to be part of the wedding.

Parents' Attitudes toward Their Experience

During the course of the interviews, these parents commented at length on their feelings about their experiences as the parents of special-needs children. They also talked about what their special-needs children meant to them. Many of the participants indicated that they saw their special-needs children as a gift from God and an inspiration to their families. Others appeared to see their experiences with their special-needs children as not all that different from the experiences of having nonhandicapped children or seemed to view their experiences with a certain ambivalence. Still others expressed a note of bitterness or resentment as much for their children's being robbed of a normal childhood as for their own difficulties. Most of these parents seemed to experience a combination of these attitudes.

Several of the parents interviewed used words like "miracle," "gift from God," or "inspiration" when describing their special-needs children and their experiences as the parents of these children. Mrs. Dias conveyed her deep feelings this way:

> Nelson didn't die because I believed that God didn't want him to die. It wasn't time for him to die. God wanted me to take care of Nelson. He knew how much we loved Nelson. I think that Nelson is a gift from God and a miracle from God. He is my angel. My husband says that Nelson is our Baby Jesus.

As Mrs. Dias spoke, she had a faraway look in her eyes; and even though she did not cry, her eyes were filled with tears.

Mrs. Gomes actually did cry when she spoke of her feelings about her daughter and about being a parent of a special-needs child. She felt that her daughter Dolores was a blessing and that God had given Dolores to her because He knew that she was the right person to take care of a handicapped child. Mrs. Duarte said that she had always accepted Carlos's disability and thanked God that Carlos was the way he was because she felt that he could have been worse. She pointed out that Carlos was an inspiration to the whole family.

Mrs. Paiva also said that she thanked God that her daughter Elia was the way she was because many children were worse off. She had visited many special-education schools and realized that there were many children whose conditions were a lot more serious than Elia's. Mrs. Tavares admired her son Bruno's will to survive. She recounted that Bruno was the only one of triplets to live and that the doctors had said that Bruno had only a minimal chance of survival. Reflecting on the progress that Bruno had made, Mrs. Tavares said that when Bruno was born, if someone had told her that he would come as far as he has, she would not have believed it. She called Bruno "a miracle baby."

Many of the parents indicated that they tried to treat their special-needs children as normally as possible. Mrs. Paiva said that, in fact, there was little difference between having a handicapped and a nonhandicapped child:

> Elia is really no trouble. She is as much trouble as a normal kid. I know what she likes and doesn't like and what she can and cannot do. I treat my handicapped child

> the same way that I treat the others. I treat her as if she was normal.

Mrs. Castelo agreed:

> We just treat Benito the same. That's what we are supposed to do. We have to treat him as normal as possible. It was hard at the beginning, but he understands more now. We try to treat him the same, but in some ways he is not the same. It is hard.

Of all of the parents, Mr. and Mrs. Xavier expressed the most ambivalence about their experiences as parents of a special-needs child. They indicated that they tried to live their lives as normally as possible; however, they admitted that having a special-needs child had changed their lives completely:

> Mr. Xavier: Jorge has completely changed our lives. We try to live as normal as possible. If he were a normal young man, I would give him five dollars and he would go wherever he wanted to go, but we can't do that with him. We have to take him everywhere.
>
> Mrs. Xavier: Actually, it is a pleasure to do things with Jorge. Having a handicapped child really changes a person's life. Unfortunately, our life is a trauma.

Mr. and Mrs. Xavier said that they loved their son very much, and they felt that Jorge gave them a lot of love and happiness. They seemed to be more acutely aware of the changes in their life-style brought about by the demands of caring for a special-needs child than did the other parents. Perhaps this was because in Portugal Mr. Xavier had been a well-known officer in a church organization and, as such, had a certain social position. He was keenly aware of what he had lost in coming to the United States to secure an education for his son: "Here I am nobody. I'm just a simple pastor of a little church."

Having a handicapped child was described as bringing profound changes to Mrs. Davila's life. She and her husband had given up their good jobs in Portugal in order to come to the United States to seek help for their daughter Sonia. Mrs. Davila seemed angry and resentful because, in her mind, her daughter's disability was caused by a doctor's error:

> What upsets me to no end is knowing that a doctor did this to my daughter. He robbed Sonia of her childhood and her life. If Sonia had been born handicapped, I could have accepted it. Sometimes I feel so sorry for her, not because she is handicapped, but because she can't do the things that she wants to do. We treat her as normally as possible. We don't want her to feel different.

Mrs. Carvalho said that she never thought that she would have a handicapped child. It had taken her a long time to come to terms with the fact that her son Quim had a disability:

> I can accept Quim the way he is now; but when he was little, it was really hard. I kept telling myself that he was going to get better. Well, he did, but not the way I thought. To say that it was a positive thing in my life, well, I can't say that. With time, however, I saw that Quim was helping me be a more caring person and a person who wanted to help other people who had problems. I wasn't like that at first.

Mrs. Xavier spoke for the majority of the parents when she said:

> Parents who don't have handicapped children don't understand. They just don't know. They have no idea how a handicapped child can change your life.

Mrs. Tavares said that she felt that people thought that it must be easier for her to be the parent of a special-needs child because she was in special education. She explained that as a professional, she could be detached about other people's children, but not her own.

Language Use in the Families

All of the parents in this study were born overseas and at the time of the study had been in this country for periods ranging from a year or two to almost four decades. All of these participants, even those who had come as children and had lived in this country for a long time, still spoke fluent Portuguese. Their knowledge of English ranged from fluent, in that one would not suspect that English was their second language, to very limited. The length of time in the United States was not always an indication of English proficiency.

Language Use of Parents

The participants varied in their fluency in English and in the language they preferred to use during the interviews. Four of them impressed me as being particularly fluent in English. Mrs. Castelo and Mrs. Tavares, the two participants who preferred to conduct interviews in English, had both come to this country as children and had received most of their education in the United States. Although both of them were fluent in both languages, they said that it was easier for them to talk about special education in English because both were familiar with the English terminology on a professional level. The other participant who came to this country as a young child, Mrs. Paiva, made it a point to conduct the interviews in Portuguese. She explained that this was because we were both Brazilians and spoke the same language and because she had never forgotten her first language, even though she had lived in this country for almost 40 years at the time of the study. Mrs. Paiva also spoke fluent, if accented, English.

Mrs. Duarte, who had been in this country for over 20 years at the time of the study, also helped her husband run a successful business here. Mrs. Duarte seemed fluent in both Portuguese and English. She indicated that she had helped many parents with special-needs children in their dealings with schools, doctors, and social-service agencies.

The other participants varied widely in their English proficiency and preference for use. Table 2 summarizes these data regarding their language use and my impression as to their fluency in English.

Language Use of Children

It is interesting to note that all of the special-needs children whose parents were interviewed, whether born in this country or overseas, appeared to be bilingual to the extent of their abilities. The parents not only reported this fact to me, but I also had the opportunity to meet these special-needs children and talk to them in both Portuguese and English. It struck me as very interesting when Mrs. Paiva told me that of her four children, only her special-needs child, Elia, spoke both Portuguese and English fluently:

> Elia has learned to speak Portuguese very well. We only speak English in the house. My other children don't speak Portuguese, but they understand it. Elia is the only one of my children who speaks Portuguese.

Table 2

Language Fluency of Participants

Name	Years in U.S.	Interview Language Preference	English Fluency
Castelo	21	English	near native
Paiva	38	Portuguese	near native but accented
Xavier	2	Portuguese	fluent
Duarte	26	Portuguese	very fluent
Carvalho	27	Portuguese	moderate
Dias	21	Portuguese	minimal
Gomes	9	Portuguese	minimal
Davila	2	Portuguese	almost nonexistent
Tavares	27	English	near native

Both Mrs. Duarte and Mrs. Carvalho stated that all their children were born in this country and all of them spoke both Portuguese and English. It is interesting to note that Mrs. Carvalho felt that her special-needs son Quim liked Portugal and liked speaking Portuguese more than his younger brother Silvio, who she felt was more "Americanized" and preferred to speak English.

Mrs. Dias also reported that all of her children were bilingual but that her son Nelson spoke more English than

Portuguese even though she felt that he understood Portuguese very well. I found that when I spoke to Nelson in English, he responded in English; and when I spoke to him in Portuguese, he seemed to understand what I was saying but responded mainly in English using Portuguese words here and there. Mrs. Dias mentioned that Nelson could speak Portuguese when he knew that the person with whom he was speaking did not speak English.

Mrs. Gomes said that her daughter Dolores, who had come to the United States when she was nine years old, had picked up English very quickly. She reported that both Dolores and their son Antonio spoke both Portuguese and English very well. Mr. and Mrs. Xavier reported that even though their son Jorge was born in Portugal, they spoke to him mainly in English:

> Jorge doesn't have much speech, but he can understand and speak Portuguese very well. Because he does everything in English at school, we speak to him mostly in English. But we also speak to Jorge in Portuguese. My wife and I speak to each other in Portuguese.

The Davilas, like the Gomes and Xavier families, had come to this country to get help for their special-needs child, Sonia. Mrs. Davila said that although her children were just three years old at the time of the interviews, they had already started to make progress in English:

> My triplets are only three years old, and they don't have much language yet. Sonia is just starting to talk, and she is already speaking both Portuguese and English. She has no trouble separating the two languages. She knows that she speaks English at school and Portuguese at home. The other two children speak Portuguese, and they are now picking up English.

Mrs. Tavares reported that her son Bruno, who was four years old at the time of the interviews, could speak both Portuguese and English well and that her 16-month-old daughter Nina could already differentiate between Portuguese and English even though she was just learning to speak. Mrs. Tavares also mentioned that they were already introducing a third language to Bruno:

> Bruno knows his alphabet in English and in Portuguese. He is a very bright little boy. Anything he knows in English he is able to translate to you in Portuguese. He can ask me for things in English or Portuguese. He is totally bilingual, in my sense of the word anyway. My husband is teaching him French now because he is a French major and he wants Bruno to speak French also.

From what Mrs. Castelo said, English seemed to be taking over as the dominant language in her household. Even though she had initially tried to speak Portuguese to her oldest child, once her daughter entered school, the emphasis switched to English. Although Benito did not have any recognizable speech, he seemed to understand things in both languages:

> We mix everything together at home. Benito doesn't even talk. Nei understands Portuguese, but he doesn't speak it because when I have to do the homework, it is all in English. So it is very hard for me to talk to them in Portuguese.

Concern for the Children's Futures

Most parents think about their children's future. For these parents of special-needs children who are especially dependent on them, concern for their children's future often seemed to take on an added dimension: "What would happen to my child when I am no longer here to take care of him or her?" All the parents in this study, even those with very young children, said they had to think about their special-needs children's future. Another common theme expressed by many of these participants was a desire that their children be as independent and happy as possible. To a number of these parents, being independent also seemed to mean their children have jobs that were suited to their abilities.

The most extreme example of concern for her child's future was expressed by Mrs. Carvalho. She said that the only thing that she was concerned about was her son Quim's future. Her younger son Silvio had offered to take care of his brother after their mother died, but

> I don't want Silvio to carry that burden. I always tell everyone that if something happens to me and God has to take me first, please take Quim the next day. Please don't leave him here without me.

Mrs. Paiva indicated to me that all she thought about was Elia's future and that she was already preparing for it. At the time of the study, Elia was about to graduate from a special-education school and was going to enter an adult recreation program at a cerebral palsy center. Mrs. Paiva described that there Elia would learn, among other things, how to set a table and do laundry. Mrs. Paiva also added that she would like her other daughter or her daughter-in-law to take care of Elia if anything happened to her or her husband. She felt it was important that Elia was taken care of by a woman because of her physical needs.

Mrs. Davila said she wanted Sonia to have the best life that she could have:

> I want Sonia to be as independent as possible because when we get old, we won't have the strength we once had, so it will be very difficult to take care of a handicapped child. However, I will go to the end of the earth to help her.

Mrs. Dias and Mrs. Gomes echoed Mrs. Davila's sentiments. Mrs. Gomes explained that she wanted Dolores to be independent because she felt that she would not always be there to look after Dolores:

> I always tell her that she has to help me around the house because she needs to learn to be independent. I told her that one day I am going to die and she has to learn to do things for herself. She is not going to have a maid to take care of her, so she has to learn to live on her own.

The Xaviers said that they would base their decision to stay in the United States or return to Portugal on whether or not Jorge found a job that would suit him. They were concerned that Jorge had come to the United States at such a young age and he might have trouble adapting to life in Portugal. Mrs. Carvalho also mentioned that she and her husband would consider going back to Portugal if Quim could not find a job that was better suited to his abilities than the one he then held.

Work also figured prominently when Mrs. Duarte spoke about her son Carlos's future. She and her husband planned to find Carlos work in the family business. Carlos had said that he did not want to go to a sheltered workshop, and they certainly did not want him to stay home doing nothing.

Mrs. Tavares and Mrs. Castelo, the two youngest mothers in the study, did not seem to think as far into the future as many of the other participants. Mrs. Tavares expressed her hope that her son Bruno, who was four at the time of the study, would be in age-equivalent classes by the time he reached the fourth or fifth grade. She looked forward to encouraging Bruno's musical talent and to nurturing a hope that Bruno might some day have some usable vision. Mrs. Castelo emphasized that she wanted to make her son Benito's life as normal as possible. She wanted Benito to be able to do things on his own and not have to depend on others.

Thematic Discussion

Many themes are implicit in the findings presented in this chapter. I have selected five that seemed particularly salient and relevant to the central focus of this study for discussion:

Theme 1. Having a handicapped child required tremendous adjustments for our family.

For most of the parents, shock was their first reaction upon learning that they had a handicapped child. For many of them, this shock was mixed with or soon followed by feelings of disbelief and sometimes anger. Several of the parents reacted to the shock of having a special-needs child by rebelling against everything they believed in, including, for a brief time, God Himself. Some became angry and blamed themselves for their child's conditions, while others, Mrs. Davila in particular, blamed their child's condition on doctors' errors. However, shock, pure and simple, whether or not followed by any of those other feelings, was the first reaction.

Several authors (Gargiulo, 1985; Hardman, Drew, Egan, & Wolf, 1993; Rose, 1987; Turnbull & Turnbull, 1990) have stated that shock is almost always the initial reaction of parents on learning they have a special-needs child. These same authors also mention a whole range of possible feelings that may be experienced by the parents to a greater or lesser extent. These feelings include anger, denial, disbelief, fear, depression, and questioning of values. All of these feelings were expressed to some extent by the parents in this study, with the possible exception of the questioning of values. Although some of the parents questioned why they had to have a handicapped child, and only a few referred to a temporary questioning of their religious faith, most of them came to regard their child as a blessing, as is expressed in Theme 4 below. Turnbull and Turnbull (1990) and Baca and Cervantes (1989) point out that religious belief is one factor that affects the parents' attitudes about having a handicapped child. The strong religious faith I observed in the lives of this particular group of participants could well have supported their basic values and beliefs in these times of crisis. Seligman and Darling (1989) do, however, use the term _anomie_, which means a sense of nothingness and meaninglessness, which is usually felt by parents when they first find out that they have a handicapped child. Those feelings were expressed by participants in this study, in particular Mrs. Davila and Mrs. Carvalho.

Several parents also said that they experienced deep psychological and emotional changes. For instance, Mr. Xavier seemed to be ambivalent and resentful that he had had to leave a good job and social position in Portugal. Mrs. Davila stated that the birth of her triplets, one of whom is severely handicapped, had radically altered her life while the family was still in Portugal. Coming to this country and having to ask for help from others only exacerbated her already changed life. Mrs. Gomes, who was a professional in Portugal, felt that she had lost both status and income when coming to this country because she could not work in her profession here. These last two participants seemed to be more accepting of the changes in their lives. They explained that although their lives had completely changed, they were here for their children, and because of that they were able to cope with the changes. Mr. Xavier, on the other hand, seemed to have hopes that someday his life would go back to the way it had been.

Thomas, Correa, and Morsink (1995) note that families with handicapped children were once viewed as pathological and in need of help to come to terms with the disruption caused by having a child with special needs. They go on to say that the research community now views such families as being as well-adjusted as any other families. Wilgosh (1990) points out that even though parents of children with disabilities have strong feelings about their situation, the most striking feature of such families is their ability to cope with these feelings and get on with their lives.

In the literature, there are discussions of changes in family relationships that may occur when parents find out that they have a child with special needs. For instance, Hardman et al. (1993) speak of the strong dyadic relationship that may develop between mothers and their special-needs children. Leigh (1987) also speaks of the strong and often impenetrable bond that can occur between a mother and her child with special needs. Many of the mothers in this study displayed a very strong affective bond with their special-needs children as described by the literature.

Most of these parents reported that their lives changed also in the sense that their children with special needs became the focus of most of their energies. This was not just because the children required more care, as discussed below in Theme 3, but also because they felt that getting the appropriate services for a handicapped child required a great deal of knowledge about their child's disability and contact with the educational system. Almost all the parents said that their involvement in the lives of their handicapped child took more time and effort than their involvement with their nonhandicapped children.

Theme 2. I could not make the doctors listen to me when I tried to tell them that there was something wrong with my baby.

Turnbull and Turnbull (1990) state that the literature is full of examples of professionals who ignore parents' perceptions about the possibility that their child might have a handicapping condition and dismiss the parents' questions by saying that their child will grow out of it. Gargiulo and Graves (1991) and Gargiulo (1985) state that physicians are often criticized by parents for not diagnosing their child's handicapping condition sooner. Some parents also blame professionals for causing the child's handicap (Gargiulo, 1985), and this was reported by one parent, Mrs. Davila, in this study. Schultz (1987) also points out that professionals do deny the parents' perceptions and knowledge about their own children. Hardman et al. (1993) mention that even when the professionals suspect a handicapping condition, they must often wait before they can make a confirmed diagnosis. They add that parents who suspect there is something wrong with their child are often forced to wait and agonize while the professionals make that final diagnosis. Kroth (1985) speaks about the insensitivity of many professionals when communicating "bad" news to parents. He asserts that because of the physicians' lack of training in delivering "bad" news, they very often talk without listening. Gargiulo (1991) makes the point that "when professionals are able to demonstrate empathy as well as respect for the parents' perspective of exceptionality, misinterpretation of parental actions diminishes" (p. 177).

Theme 3. My special-needs child requires a lot of extra help and attention.

Beckman (1983) found that much of the stress experienced by mothers of infants with special needs was a result of the demands of the special care that these children required. He also emphasized the continuing needs of older special-needs children such as feeding, bathing, dressing, and the like as activities that may cause a great deal of stress to the parents. Although most of the parents in my study mentioned that taking care of their special-needs children was and can be stressful to them, many of them also reported that taking care of their special-needs children was really a pleasure for them and they enjoyed doing so. Mrs. Davila expressed that spirit of dedication when she said, "As soon as I found out about Sonia's disability, I stopped living for myself and started living for her."

Researchers have also indicated that the burden of care of special-needs children usually falls disproportionately on the mothers (Willer, Intagliata, & Wicks, 1981) but that fathers and siblings are playing an increasing role in the care of the special-needs children (Hornby, 1988). Swenson-Pierce, Kohl, and Egel (1987) mention the role that siblings play in helping handicapped children. Thomas, Correa, and Morsink (1995) and Navarette (1996) state that the traditional view of parent involvement as being mainly for mothers must be expanded to include fathers, siblings, grandparents, and other caregivers. In this study, I have found that at least two of the fathers were quite active in the daily care of their special-needs children. Mr. Xavier was remarkably involved in the care of his son Jorge, who has Down syndrome, to such an extent that he seemed to supplant his wife as their son's primary caretaker. Mr. Dias, who because of his own disability was not able to work, was responsible for much of the day-to-day care of all his children, including his son Nelson who had Down syndrome. I also found that many of the siblings were described as the handicapped children's best friend and were a positive influence and a great help to those children.

Swenson-Pierce, Kohl, and Egel (1987) report that with time and as the special-needs children get older they often require less care because they learn more self-help skills. Turnbull and Turnbull (1990), on the other hand, point to the continuing needs of older special-needs children with physical disabilities such as feeding, bathing, dressing, and the like as activities that may cause a great deal of stress to parents. They state that this is because these are activities that nonhandicapped children learn to perform without help. Kirk, Gallagher, and Anastasiow (1993) also refer to the difficulties experienced by parents when caring for handicapped children, especially in the areas of feeding and dressing. Many of the parents in my study experienced little or no decrease in the help and attention they gave their special-needs children. Mrs. Paiva, Mrs. Carvalho, and Mrs. Gomes, who were among the parents who had special-needs children who were older, reported no diminution in the care they had to give to their handicapped children. They still had to help their children a great deal physically in the same ways they had to help them when their children were younger.

Among the parents of younger children, it is hard for me to imagine that there will be much decrease in the care that Mrs. Davila has to give to her daughter Sonia who is confined to a wheelchair. This could also apply to Mrs. Castelo, whose son Benito is autistic, and her struggle with his inappropriate behavior and his lack of understandable speech, and to Mrs. Tavares, whose son Bruno is blind and has serious developmental delays that require constant medical care. The amount of care that these children need has a great effect on issues of parents' involvement in education, which is the topic of the next chapter.

Theme 4. The learning problems of these children have not prevented them from learning a second language.

In the course of conversations with the parents and children, it became apparent that the special-needs children were bilingual to the extent of their language development. What appeared to me to be the most striking feature was the way that these parents accepted these children's having learned a second language as something natural. Most of the parents seemed to view their special-needs children's language fluency in Portuguese and English in much the same way they viewed the language development of their nonhandicapped children. For most of these parents, fluency in both languages for all of their children, including their children with special needs, was just a normal part of their children's development.

It is interesting to note that in some of these families the children who seemed to be most proficient in speaking both languages and who had the greatest interest in the Portuguese language and culture were the children with special needs. This was particularly striking in the case of Mrs. Paiva, whose daughter Elia was the only one of the children in the family who spoke both Portuguese and English fluently. Mrs. Paiva said that, in fact, her other children understood Portuguese but did not speak it because they preferred to speak English. It seemed to me that this interest on the part of the special-needs children might be due to the close ties with their parents, especially their mothers (Hardman, Drew, Egan, & Wolf, 1993, p. 421), and the fact that their parents took them "everywhere," while their more "normal" siblings might be more involved in their peer culture. A few of the families, however, reported that even though their children with special needs could speak both languages, or at least understand them in those cases where the child had little or no speech, these children preferred to communicate in English. Mrs. Davila's daughter Sonia, who was three years old at the time of the interviews, could already speak both Portuguese and English and knew that she spoke Portuguese at home and English at school. At the same time, Sonia's nonhandicapped siblings were just starting to learn English.

Cloud (1994) cites Ratleff (1989) that there are three equal factors that must be taken into consideration when teaching a second language to special-needs children: the handicapping condition, the language characteristics, and the cultural characteristics of the children. In other words, the first language of the child and his or her culture should be taken into consideration along with the child's handicapping condition in order to teach him or her a second language effectively. I find it interesting to note that from what I was told about the experiences of the children in this study, their linguistic and cultural characteristics were definitely not given special consideration. None of these children was in a bilingual special-education program because no such program was available in Portuguese. I would not want to argue that the findings of this study indicate that the elements presented by Cloud and Ratleff should not be taken into consideration. I do, however, want to make the point that these children have strengths that are often not recognized.

Carrasquillo and Bonilla (1990) note:

> There is very little literature dealing with the teaching of a second language to children who have language deficits in their primary language.

They also point out that there is no evidence that learning a second language has any negative effects on the development, either cognitive or academic, on children in special-education programs. Cummins (1983) states that although the acquisition of a second language might be more difficult for children with learning disabilities in their first language, they are able to learn a second language. He goes on to say that acquisition of a second language by these children is neither too difficult nor inappropriate. The experiences of the children in this study certainly support the thesis that children with special needs can learn more than one language successfully. These children were not only able to learn a second language, but in some cases were able to maintain their first language better than their nonhandicapped siblings.

Theme 5. This child has been a gift from God.

There is mention in the literature of a questioning of values by parents who endured the shock of having a child with special needs (Turnbull & Turnbull, 1990), as has already been discussed above under Theme 1. However, this questioning seemed less prevalent and more short-lived among my participants than might have been observed in other populations. What was, in fact, particularly striking was the extent to which these parents had come to view their children with special needs as a blessing and a gift from God. Some of these parents, Mrs. Duarte in particular, thought that their special-needs children have helped strengthen the bonds among other members of the family, making the family stronger and more united. Several of the parents believed that God had chosen them to be the parents of special-needs children because He knew that they were people who would be able to care for these children properly. As noted previously, Mrs. Dias had said, "God wanted me to take care of Nelson. He knew how much we loved Nelson." Mrs. Gomes echoed this sentiment, and Mrs. Duarte believed that Carlos was an inspiration to the entire family.

In all of the sources I have cited, however, there has seemed to me to be more of an emphasis on the difficulties experienced in families with special-needs children than on the positive aspects reported spontaneously by my participants. The one exception was Correa (1989), who pointed out that professionals need to take into account cultural beliefs when intervening with families of diverse backgrounds:

> Families may believe that the birth of a handicapped child is a blessing from God and thus be extremely positive about having the child. Professionals who assume that all families of handicapped children are in need of family counseling and skills for coping with the tragedy are insensitive to the cultural beliefs of the family.

Baca and Cervantes (1989), in their discussion of attitudes of parents toward handicapped children, cite earlier studies that indicate there is a positive correlation between religious belief and maternal acceptance of handicapped children and that Catholic families appeared to be more accepting than others. Possible reasons suggested for this acceptance were the Catholics' "failure to associate blame with the birth of a handicapped child" or "the Catholics' belief in suffering as a part of life" (p. 320). None of the participants discussed the specifics of the religious beliefs that might support their attitudes. It does seem reasonable to me to assume, however, that they expressed their feelings for their children in the religious terms common in their Catholic culture. I also felt that perhaps they might not have given a religious interpretation to their experiences if they had not known that I shared this culture.

The Xaviers, the Protestant family among the participants, were also openly religious. Mr. Xavier was a minister who had been well known in the Portuguese Protestant community. Although he was most vocal about what he and his wife had given up for their child, he claimed that their religious faith had "helped them cope."

In general, it was my impression that the attitudes in these families were more positive than an earlier reading of the literature had led me to expect. This is another of the strengths of which educators need to be aware, and I will return again to this topic in the final chapter.

CHAPTER VI

THE FAMILIES AND THE CHILDREN'S EDUCATION

The initial question guiding this research project concerned the attitudes of the Portuguese-speaking participants toward involvement in the education of their children with special needs. As the findings in the previous chapter indicate, the participants had much to say about their experiences as parents of special-needs children. They also, however, had much to say about their experiences in the schools and about parental involvement in education as well, and that is the topic of this chapter.

Portuguese-speaking Parents in an Urban School District

As has been mentioned earlier, the participants in this study were all first-generation immigrants. Four of the ten participants came as children in families who were seeking to better their lives. Of the six who came as adults, two came to better their lives and one, Mrs. Duarte, came on her honeymoon and decided to stay. The other three came specifically to seek help for their special-needs children. Regardless of why or when they came, they all shared the common situation of being foreign-born parents for whom English was a second language. Among findings presented in this section are ways in which their ethnic heritage and language abilities were manifested as they attempted to function within networks of social services and a large urban school system.

Ethnicity and English language fluency are often seen as factors by parents in their dealings within school systems. This was true for the participants of this study, perhaps to a greater degree than for most parents, because the needs of their children were so much greater. All spoke at length about what they perceived as the advantages and disadvantages of schooling in the United States for their special-needs children. Some also expressed the opinion that their ethnic background or language ability hindered their getting the kinds of assistance they sought.

Advantages and Disadvantages of Schooling in the United States

Those parents who came to the United States especially because of their special-needs children were in a position to compare special education in the United States with that of Portugal because they have had firsthand experience with the special-education system in both countries. All three of the parents expressed the opinion that special education was better in the United States than in Portugal and that their children were better off in this country. They all said that even though their lives had been much better in Portugal than it was in this country, they felt that their "sacrifice" had been worth it because of the level of education and services that their children were getting in this country, which was superior to that in Portugal.

Mr. Xavier, who had had the greatest experience with special education in Portugal, was particularly critical of the system there:

> There are no courses or programs for students who want to go into special education in Portugal. We have teachers who are very affectionate and who have good intentions, but who are not qualified. We do have special-ed[ucation] schools. They are all private and subsidized by the government, and the quality of instruction is very weak. I think that special ed[ucation] in Portugal is almost nonexistent. It is the general-ed[ucation] teachers who teach these children. Special ed[ucation] in Portugal is a miserable disgrace. The special-ed[ucation] system here is very good, but there is always room for improvement.

Mrs. Davila was also very critical of the special-education system in Portugal because she felt that in Portugal parents were kept in the dark about their children's conditions. She also said that she thought that professionals (in her case, mainly physicians) were extremely pessimistic about what special-needs children could achieve with proper treatment:

> The doctors said that Sonia would never talk, walk, or even eat by herself. It is better for her here. She is doing much better. She is talking, and she is eating almost by herself.

Mrs. Gomes appeared to have a much more positive opinion about special education in Portugal saying that she thought that there were some good special schools and teachers there. It is interesting to note, however, that her daughter Dolores had not attended a special-education school in Portugal. Being of normal intelligence and able to walk with the aid of a brace, Dolores had attended a regular school there. Dolores did, however, receive special services in Portugal. These services included Dolores's medical treatment and braces and, when she was a baby, even her diapers. Mrs. Gomes felt that, in general, the services her daughter received were better in this country, but that it was a struggle for her to get the best services for her daughter. She mentioned that in Portugal everything had been provided without charge, whereas in this country she felt that services were much more difficult to obtain, especially for someone who had neither the insurance nor the money to pay for them.

All the other children whose parents participated in this study were born in this country, and, therefore, their parents did not have the same firsthand experiences with the special-education system in Portugal as the participants cited above. All the parents in this group say that they return to their homeland for vacation. Those who could afford it went back every year, if only for a short time. The others went infrequently. They all told me that they had taken their special-needs children with them, with the exception of Mrs. Tavares, whose son Bruno was born after her last visit to Portugal. The participants reported that their special-needs children enjoyed visiting their parents' homeland and that those children who were old enough to remember looked forward to those visits.

Most of the participants in this study expressed the opinion that their special-needs children were getting a better education in this country and that the special-education system in their country (whether in Portugal or Brazil) was not as advanced as that in America.

As a special educator, Mrs. Tavares was perhaps in the best position of all the participants in this group to make a comparison between special education in this country and in Portugal:

> As far as special education in Portugal, well, I don't think that Bruno would do well there. They are not as advanced as we are here. They are to the point now that we were in 1975. They are just now starting to classify children. If the children don't have the obvious handicapping conditions like blindness, mental retardation, or deafness, they don't know how to classify the children.

Language and Ethnicity as Barriers for Parents

Three of the participants in this study addressed the issues of language and ethnicity as barriers to obtaining services for their special-needs children. These three parents provide a cross section of all the parents when it comes to their language ability. Mrs. Gomes spoke very little English, although she had lived here for almost ten years at the time of the interviews. Mrs. Gomes said she did not think that the schools in the Portuguese community where she lived were as good as the schools in a neighboring town where she had lived earlier where the population was largely American. Although the Portuguese community where Mrs. Gomes lived was but a small section of a large city, Mrs. Gomes believed that there was a general lack of interest on the part of the board of education and a lack of cooperation between the board and the community. She also said that she noticed that there was a lack of communication between the board and the parents and suggested a way to remedy the situation:

> The Portuguese people are not well represented here. We need an advocate for us because the parents complain and the board doesn't do anything. The Portuguese parents have to learn to be advocates for themselves, too, so that they can help each other.

Mr. and Mrs. Xavier lived in a town adjacent to that which had the main Portuguese community and, therefore, they dealt with a different board of education from Mrs. Gomes. However, like Mrs. Gomes, Mr. Xavier expressed the belief that there was a lack of cooperation between the board of education and the schools in his district. He also said that the Portuguese people were not well represented on the board:

> There isn't anyone there who speaks Portuguese and who could help us. When the board of ed[ucation] says that the parents are welcome to go and talk to them about any problem that we have, it is just to say that they are doing something when, in fact, they don't do anything. It is just a formality. I found that it was a waste of my time to go to the board. The law says that they have to listen to the parents, but they don't. If they don't help the American parents with their problems, they certainly are not going to help the Portuguese parents.

Mr. Xavier said that he was speaking from his own experiences of dealing with the board of education. He recounted that he had had a problem with his son and had gone to talk to the social worker and his son's case manager, and he felt that they did not listen to what he had to say. He said that this experience was so frustrating and such a waste of his time that he would probably not bother to go the next time he was called for a meeting.

Mrs. Tavares worked in the school system of the city with the large Portuguese population. She spoke not only about her experiences as a parent of a special-needs child, but also about her observations of how the professionals dealt with the Portuguese parents. Mrs. Tavares believed that the Portuguese parents did not really understand the nature of special education and what it meant for their children. She found that many of the parents either took the attitude that their children needed to be in special education because they were a little slow or, at the other extreme, because they were severely retarded. She did not think that the Portuguese parents in general were knowledgeable about their rights, especially when it came to obtaining services for their special-needs children. She went on to say that most of these parents still had the old-world Portuguese mentality that the schools knew best and would do whatever was necessary for their children. She suggested that a parent advocate might improve the situation, but that there would probably still be parents who would not ask for help:

> I think that, unfortunately, a lot of our Portuguese parents don't have their priorities right. They are afraid to speak up. They have the mentality that the school will have to do what they have to do for their children, which is not always necessarily true. I think that if they read the parents' rights and knew what their rights were and understood them, and if they didn't understand them, go to an advocacy group and get the correct details and find out. . . . It is going to take some time on the part of the parents; and, unfortunately, a lot of the parents don't take the time.

Parents Coping with the System

Besides the normal dealings that parents have with schools, the parents in this study were faced with the necessity of finding appropriate placement and services for their children. For some of these parents, finding the most appropriate placement and services for their special-needs children seemed to be a constant struggle to assert their rights and those of their children.

Mrs. Paiva's attitude was similar to that of several of the parents. Her strategy for dealing with doctors, school, case managers, and special-education agencies was:

> I have to keep after them for everything. If I don't keep after them, they won't inform me about anything. I have to do everything on my own. If I need help from the case worker, I have to keep after her. They just don't help on their own. You have to be on top of things all the time. I'm always making surprise visits to Elia's school. I have to know what is going on there. I have to make sure that they are really doing their part. I'm always going to bat for Elia. I have to, because if I don't take care of her and make sure that her needs are being met, no one else will.

Mrs. Paiva kept a file on Elia from day one. In this file, she had every document relating to Elia from her doctors, school, social worker, and so on. She said that in this way there was never a question about a diagnosis, treatment, or program for Elia. She had even added her copy of my consent form for our interviews because, in her mind, it pertained to Elia.

Because Mrs. Tavares was a professional educator working in special education, one might assume that her attitude toward the system and coping with it would be different from that of the other parents because she is, after all, an "insider." In fact, Mrs. Tavares's views of coping with the system did not appear to be all that different from Mrs. Paiva's. In a sense, being an "insider" seemed to make her even more aware of the importance of fighting for her child.

> In the position that I'm in now, I'm pretty knowledgeable about the law. I know that we have the right to fight for this. Say I want something for my child, and it is here. I fight for it. I am always somewhat involved with an advocacy group. I'm not too involved with them because I think that I am my own advocate. I know what the law says, I know what I can and cannot do, and I know what Bruno can and cannot have. I have been there for him from day one. My situation is very different because I work with all the team members and I see my son's case manager almost every day. If I were a regular parent, I would get shifted around just like all the other parents.

Mrs. Gomes and Mr. Xavier, having come from Portugal and having dealt with the system there, both felt that they had to fight for their children's rights in this country. They made the comparison with Portugal when they said that they believed that services for their special-needs children came more automatically there. Mr. Xavier said:

> I know my rights and Jorge's rights, but if we want something for him, we really have to fight for it. It is a struggle all the time. It is different in Portugal. When you have a handicapped child, you automatically have things and services for them. We don't have to fight for everything. The problem here is that the board of education in my district is not all that helpful.

Mrs. Gomes seemed to be speaking in one voice with Mr. Xavier when she discussed her struggle with the system here in this country. However, she did not seem well informed, either about her rights or her child's rights, because of her limited knowledge of English. When she talked about paying for the things that Dolores needed, I understood her to be referring to medical care and apparatus for her child.

> Being handicapped, my child had services automatically in Portugal. Here I have to fight for her to get what she needs. Also, I have to pay for the things that Dolores needs. If I have the money, I can get the things that she needs, but if I don't, I can't get anything. It seems that if I want anything done for my child, I have to do it myself.

It seemed that all of the parents "went to bat" for their children at one time or another. Mrs. Duarte said that the board of education was very helpful, and she seemed to be very happy with her son's placement. Yet she emphasized that she knew her son's rights and did what she had to for him. Mrs. Duarte had also assisted other parents, among them Mrs. Dias, who because of her limited English did not seem to be very knowledgeable about the system or her child's rights. Mrs. Davila, who had only recently arrived from Portugal, also needed help dealing with the system. Not only did she not speak English, she was also in a precarious financial situation. In fact, she told me that someone had helped her to go to the Portuguese community to ask for donations to help pay for Sonia's medical expenses.

Mrs. Castelo explained that the way she coped with the system was by reading everything she could about her boys' condition and by belonging to various organizations and support groups. She, too, had gone to the professionals when she felt that the needs of one of her sons were not being met by his school and had his placement changed. She also mentioned that

Benito's new school had an open-door policy, and she had gone there to observe him in class.

Mrs. Carvalho learned how to work with Quim by staying in his class and observing what his teachers did with him. She, too, was not shy about going to the board of education when she felt that her son's placement was not, in her opinion, what he needed.

In general, it would seem that the parents had all become increasingly aware of the range of services available to them and their children. They appreciated the fact that educational opportunities here surpassed those available in their native countries. However, they spoke with some annoyance or resentment of the extent to which they had to "fight" for what they thought was due the children. Their realization of the severity of their special-needs child's condition was a beginning step in their transformation toward becoming an advocate and being more actively involved in the child's education, which is treated in the next chapter.

Parents' Attitudes toward School Placement

As was documented in the previous chapter, many of the parents expressed the belief that their child's initial diagnosis had taken longer than it should have. After an adequate diagnosis was made, however, most of these children were referred at an early age for special therapy.

Bruno Tavares had actually spent most of his first year in a hospital for "intensive physical and developmental therapy." Mrs. Tavares continued:

> When he came home, Bruno was functioning at a week-old level. He was eligible to attend an early intervention program because of his developmental delays, but I found a loophole because he was blind. So he attended two early intervention programs. One was at a school for the blind, and it was beautiful. I couldn't say enough about it. The other program was one where the parents learned how to work with their handicapped children. He also had a home instructor who came once a week. It worked out great because one program was during the day and the other was in the evening.

Bruno, who at the time of this writing was four and a half years old, is now at a private school for handicapped children who range in age from 3 to 21. Mrs. Tavares appeared to be very satisfied with this placement:

> It is a very nice setting. It was opened by the principal, who is a learning consultant. I think his wife is also a learning consultant or a social worker, and they are very knowledgeable. They really teach the children, and it is a really educationally oriented school. It is a great school, and I'm really happy with it.

The realization that Bruno was seriously handicapped was a great emotional shock to Mrs. Tavares and her husband, as her story indicates. Because she was a professional educator, however, she already had background knowledge that would help her understand her child's problems and find appropriate therapies. Mrs. Castelo, on the other hand, in the beginning had no idea what was meant by the word used to diagnose her twins:

> That word . . . that word autistic. I didn't even know it existed. From then on, I read a lot about it and what it meant. I became a member of an organization for parents who have autistic children.

Mrs. Castelo told me that both of her twins were diagnosed as having autism; and after this diagnosis she started to look for special-education programs for them. She went to the board of education in her district, and the boys were placed in a preschool handicapped program in a regular school. Mrs. Castelo told me that when the boys finished their preschool handicapped program, Nei started to talk and seemed to show great improvement. He was then reclassified as emotionally disturbed. The school officials told Mrs. Castelo that because Nei was going to remain in a regular school, emotionally disturbed [ED] would probably be a better classification for him. He has thus been able to receive special-education services through the resource room in a regular school. Nei had finished regular kindergarten and first grade and was now doing well in second grade:

> Nei is doing second-grade reading and second-grade everything. He goes on to a resource room where he gets extra attention because that's what he needs. I think I'm happy with the school.

Benito, on the other hand, went on to a school for children with multiple handicaps. After a couple of years at this school, Mrs. Castelo felt that Benito was not improving, and she looked into another placement for him. Now Benito is in a school for children with autism, and Mrs. Castelo seemed to be happy with his placement:

> The director has a son who is autistic, and a lot of the professionals at the school either know people who have autistic children or have worked with autistic children for a long time. I am very happy with the school.

When Mr. Xavier learned that Jorge had Down syndrome, he, like Mrs. Castelo, started reading about his son's condition. Mr. Xavier explained to me that while still in Portugal he tried to use his connections as a prominent clergyman to help him find a special-education program for Jorge. The first school Jorge attended was run by a charitable organization. Mr. Xavier did not think that this school was very good for Jorge, but he kept his son there because he felt that the director was a good therapist and she was also the daughter of an important Portuguese political figure. When that director left the school, Mr. and Mrs. Xavier decided to take Jorge out. After that, Mr. Xavier said that Jorge had attended several public schools in Portugal.

On the advice of professionals who said that Jorge could get a better education abroad, Mr. and Mrs. Xavier decided to send him to live with a family friend in the United States. After a few years of traveling back and forth to Portugal, the Xaviers decided to join their son permanently. While here with the family friend, Jorge attended two other special-education schools before the school for children with multiple handicaps that he now attends. Mr. and Mrs. Xavier appeared to be generally happy with their son's current placement:

> Jorge attends a very good school now. This school's philosophy is to develop the whole person. They concentrate on daily skills such as cooking, hygiene, etc. They try to find what the children can do well so they can be trained to work later on when they graduate. This is the best school Jorge has ever attended. The teachers are

> great, and the principal really cares about the children. I am really happy with the school.

Although Mrs. Xavier seemed satisfied with her son's placement, she communicated to me that she had mixed feelings about the school's program:

> I like the school. The teachers and the principal really care about the children, but what I don't like is that they don't do anything about academics. I think that Jorge is losing what he learned at the other school. He can't read or write much anymore. At the other school, he used to have homework and we used to help him with it.

Mr. Xavier then explained that in his opinion Jorge's current school offered various types of therapies. He seemed pleased that the school offered speech therapy, which he felt Jorge really needed because of his speech problem. He went on to say that even though the school's philosophy did not stress academics, he felt that his son was being well trained to have a successful life after graduation.

Mrs. Gomes's attitude toward her child's placement seemed to be completely different from that of Mr. and Mrs. Xavier. Mrs. Gomes told me that when they lived in Portugal, Dolores had attended first a regular preschool and then a regular elementary school. She, like Mr. and Mrs. Xavier, came to the United States because she felt that Dolores would get a better education here. When she first arrived in this country, she had lived in an American neighborhood where Dolores attended a regular elementary school. When she moved to the Portuguese neighborhood where she lives now, Dolores attended a regular school. While there, Mrs. Gomes was told by Dolores's teachers that she was having trouble keeping up with the other students. It was then that the school administrators told Mrs. Gomes that they felt it would be better for Dolores to be transferred to a special-education program. Mrs. Gomes did not seem to be very happy with Dolores's placement:

> Dolores attends a regular high school that has a special-education program for children who have physical problems. I think it is the worst school that she has ever attended, and it doesn't have a lot of resources. I wish I could take her out of there and put her in a regular school. But if I do that, she won't be entitled to any special-education services. She is only entitled to special-education services if she attends a special-education class. I guess she is doing okay there. Her classes are small, and she gets a lot of individual attention. She takes two special education classes, and the rest are regular classes.

When I spoke to Mrs. Dias about Nelson's school placement, she said that she did not remember very much about his early placement. Mrs. Dias recounted only that Nelson was two and one half years old when he first attended a special school where she thought Nelson had speech therapy. Mrs. Dias's strongest memory of this school seemed to be that the school bus picked Nelson up and brought him home again.

Mrs. Dias expressed unhappiness that her son was attending a special school--this despite the fact that she readily admitted that Nelson had Down syndrome and needed to be in special education. She told me that Nelson's current school was very encouraging and that he was learning a lot there. She was pleased primarily because they had a job training program. She also said, however, that she felt that Nelson was being held back by the other more handicapped children in his school and that in her opinion Nelson would be better off in a more "normal" environment. She thought, at the time of the study, that Nelson might be transferred to a special-education high school that would provide vocational training in a more "normal" environment. At the time of this writing, Nelson was 15 years old and still had not changed schools.

When Carlos had first reached school age, he briefly attended a "regular" school. After a short time, Mrs. Duarte was told by the principal that Carlos would be better off in a special school because he was having trouble keeping up with the other children. Then, when he was five years old, Carlos went to a school for children with special needs. He was about to graduate at the time of the study. Mrs. Duarte appeared to be very pleased and even enthusiastic about her son's placement.

At the time of the study, Quim was the only one of the children who was no longer in school. He was 22 years old and had already graduated from school the previous year. Quim had attended the same school as Carlos. Mrs. Carvalho had been very pleased with the school and had only good things to say about it. Quim was now in a shelter workshop for young adults, and Mrs. Carvalho said that she was really unhappy with this arrangement. She considered it just a place to get him out of the house and to pass the time. The assembly-line work did not hold his interest for more than a few minutes at a time. She wished he could be in a place where the work would be more interesting and challenging.

Mrs. Paiva and Mrs. Davila both seemed to be pleased with their daughters' current placement. Mrs. Paiva's daughter Elia had attended a center for children with cerebral palsy from the age of six months to five years. She then went to a school for children with multiple handicaps, which she was still attending at the time of the study. Mrs. Paiva told me that Elia would soon be turning 21 and would graduate at the end of the school year.

Mrs. Davila's daughter Sonia had received physical therapy in Portugal. When the family moved to this country, Sonia attended a center for children with cerebral palsy for a short time. Mrs. Davila said that she did not like the school because, in her opinion, she thought that it was not offering what Sonia needed in terms of therapy. She also objected to the fact that Sonia would have had to leave the center when she turned five years of age, and she would have to find another school for her daughter. Sonia was only three years old at the time of the study and had recently been placed in another center for children with cerebral palsy where Mrs. Davila was told that her daughter could remain until she reached the age of 21. Mrs. Davila was very enthusiastic about the program, both for its continuity and because she felt it offered the types of therapies that Sonia needed.

Types of Parental Involvement

All the participants in this study were involved in their children's education in many ways. The involvement took place in two different spheres, the home and the school. Activities in the home included performing therapies on their special-needs children, taking the children on outings and exposing them to the world, and helping them with homework and other projects directly related to what the children were doing in school. Activities in school included, but were not limited to, the more traditional types of parental involvement: parent-teacher association meetings, parent-teacher conferences, help with fund raising, and the like. No matter what form the involvement took, these parents seemed to believe that their involvement was important for their children's education.

Educational Involvement in the Home

The parents in this study participated in many activities at home that could be seen as being related to their children's education. In fact, many of these parents indicated that participation in activities at home was as important as participation in activities at school, if not more so.

Therapy

Because these children had special needs, giving them therapies at home was an important type of involvement for many of their parents. Although some of the parents were not doing any type of therapy with their children at the time of the study, seven out of nine families reported that they had done so, especially when the children were younger. At the time of the interviews, those parents with the youngest children were the ones most actively involved in their children's therapy.

Mrs. Davila reported that she did therapy with her daughter Sonia on a daily basis. Sonia had both speech and physical therapy at school as well as with a private physical therapist.

> Sonia's private therapist is always teaching me how to do the therapy at home. The therapists at school don't teach me anything. I think they know that I do therapy with Sonia at home, so they just tell me to continue doing it. I always do her therapy before her bath, before I put her to bed, and also when we are playing with her.

Sonia's brother and sister "helped" with the therapy by doing it on each other and on their dolls. Mrs. Davila also said that she talked to Sonia all the time and encouraged her to talk.

At four years old, Bruno Tavares had already been in two early intervention programs. Parent participation in these programs was mandatory--parents were required to attend to learn the therapies and also to learn how to deal with a handicapped child in general. Bruno had a home instructor from the State Commission for the Blind, who came to their home to work with them on Saturdays. At the time of the interviews, Mrs. Tavares said that Bruno was in school and had almost all his therapies there. However, this did not prevent her from working with her son at home.

> I try to do a lot of teaching with him. It is more play. We do the alphabet; we do numbers. I find myself always teaching him something. . . . We are always talking to

> him. During bath time we teach him how to wash himself. We put everything into songs since he loves music.

Benito Castelo's teacher came to their house to show his mother how to work with Benito by means of positive reinforcement. The teacher also tried to help them communicate with each other by teaching them simple signs and words. Mrs. Dias said that her family tried to help Nelson with his speech by constantly talking to him and asking him open-ended questions that Nelson could not answer with a "yes" or "no." Mr. and Mrs. Xavier told me that Jorge's teacher had tried to teach both him and his wife sign language in order for them to work with their son at home. Mr. Xavier then explained that he had been unable to learn very much sign language and, therefore, Jorge's teacher had told them to talk with their son as much as possible and encourage him to respond in order to develop Jorge's speech as much as possible.

Mrs. Carvalho reported that she had performed physical therapy with her son Quim when he was younger. She had learned to perform the therapy by watching the therapist work with Quim at school. It was only when the teachers noticed that Quim was progressing faster than they had expected that they asked her if she had been working with him at home. The therapist asked Mrs. Carvalho to show her what she was doing with Quim, and when she ascertained that Mrs. Carvalho was performing the therapy correctly, she encouraged her to continue working with her son at home.

Mrs. Paiva still performed physical therapy with her daughter Elia, who was 21 at the time of the study. She mentioned that she had asked Elia's physical therapist for information about the therapy that Elia was receiving in order to be able to work with her at home. Mrs. Paiva had placed a copy of Elia's exercise chart on the door of the refrigerator for quick reference.

Outings

Almost all the parents in this study thought that taking their special-needs children on outings was an important way to expose them to the world. They believed that exposing their children to the world would help them interact with people outside their families and enable them to lead normal lives to the extent possible. When Mrs. Castelo said, "I take Benito everywhere with me," she was speaking for the majority of the participants. Mrs. Paiva used almost these exact words when talking about her daughter Elia. Mrs. Dias, Mrs. Carvalho, Mr. Xavier, Mrs. Duarte, and Mrs. Tavares all said that they made it a point to involve their special-needs children in outings and family activities outside the home. It was not only the parents who were involved in getting these children included in such activities. Mrs. Gomes and Mrs. Duarte both reported that their other children played an important role in involving their special-needs siblings in activities outside the home.

Homework

The word homework often brings to mind images of children performing tasks in such traditional subjects as math and reading at home. These tasks are usually assigned by the teacher to reinforce the day's lesson or to prepare the children for a new lesson. For a few of the children in this study, homework followed this traditional pattern, and the parents helped their children with their homework in much the same way they helped the other children in the family. For most of the parents in the study, however, helping their special-needs children with their homework took a less traditional but no less important form. For these parents, this often meant trying to keep the children mentally active, trying to communicate with them and encouraging the children to communicate, and/or performing a therapy that helped reinforce the therapy that their children received at school.

Mrs. Gomes said that because of her limited knowledge of English, she helped her daughter only with reading and writing Portuguese. She said she felt it was important for her daughter to be literate in her native language. When it came to other subjects, it was Dolores's older brother, a college graduate in this country, who helped her.

Both Mrs. Duarte and Mr. Xavier reported they had helped their children with their homework in the past but were no longer doing so. Mrs. Duarte said that she had helped Carlos while he was learning to read. The Xaviers indicated that Jorge's previous school had an academic emphasis and that they had helped their son with reading and writing. Jorge's current school emphasized daily-living skills, however, and helping Jorge with his homework now meant working on Jorge's communication skills. Because Quim could not read, his teachers told Mrs. Carvalho to provide him with picture books and to encourage him to make up stories about the pictures. Although Quim could not write, he could trace and copy letters and words, and he had often done so while his younger brother was doing his homework.

Mrs. Castelo helped her son Benito with his homework by encouraging him to communicate and working with him in identifying simple words and pictures using flash cards. Mrs. Paiva expressed an attitude of dedication toward the needs of her special-needs child that was common to many of these parents when she said:

> When Elia is home, I have a lot of coloring books for her. She loves to color. . . . I always have things for her to do. We try to teach her things, but she doesn't remember things. But we go on trying.

Even though Mrs. Dias's son Nelson did not have homework in the traditional sense, she was encouraged by his teachers to provide him with materials to trace and draw. Mrs. Dias said these were activities that Nelson was good at and liked to perform. According to Mrs. Dias, Nelson did his "homework" while his sisters did theirs. What appeared to be traditional about Nelson's homework was Mrs. Dias's attitude toward it. She explained that she did not "help" any of her children with their homework because she felt that it was their responsibility. What she did do, however, was to make sure that her children completed their homework assignments. She and other participants told me that they felt that this was the "traditional" Portuguese attitude toward any child's homework.

Parental Involvement in School

Upon reviewing the data for the involvement of these parents in their special-needs children's school, I was interested to find just how "normal" this involvement was. I found that the involvement of most of these parents seemed to be very similar to that of any parent in any child's school. The feature that stood out was that many of them seemed to be very involved in their children's education. For the most part, these parents appeared reasonably well informed about the opportunities for participation by their special-needs children's schools. From what they told me, most of them were taking advantage of the opportunities for involvement offered by the schools. Mrs. Paiva was by no means atypical when she said: "I'm involved in everything. I'm involved in the school. If they need anything done, I'm there. . . . Everyone knows me at the school."

Mrs. Paiva frequently dropped in at Elia's school whenever she "just happened to be in the neighborhood." She had previously told me that Elia's school was located on the other side of town, a considerable distance from where she lived:

> I also make a lot of surprise visits to the school. I want to know if they are really doing what they are supposed to be doing for my child. I'm always in touch with the

> teachers. If Elia has a new teacher, I want that teacher's phone number so I can call her and get to know her.

Many of the participants said that their children's schools had an "open-door" policy and that they made frequent unannounced visits to their children's classes.

Mrs. Castelo's participation was an example of the varied types of activities that many of the parents in this study were involved in at their special-needs children's schools.

> I try to go to all the conferences at Benito's school. I try to keep in touch with the teachers so that I know what is going on and what they are doing with him. The school has an open-door policy, and you can go in to visit anytime you want. They have an art auction every year to raise money for the school. Everybody is involved in the committees. They want everyone involved. They also have scouting there. They have a home-school association, which I am a part of. They allow you to help in the classroom and with field trips. I try to do as much as I can. Sometimes it is hard because I work, but if it is after two in the afternoon, I can be there to help.

A limited knowledge of English was by no means an insurmountable obstacle to these participants' involvement in their special-needs children's education. Even those participants with the most limited command of English seemed to be able to keep abreast of developments. Mrs. Dias and Mrs. Davila both said that when they went to meetings at their children's school, they usually took a family member with them to act as interpreter. Although Mrs. Gomez did not attend many meetings at Dolores's school, she was in frequent telephone contact with her daughter's program coordinator.

For Mrs. Dias and Mrs. Gomes, who did not drive, transportation was a barrier to their participation because their children attended schools that were far from their homes. They also said that their children attended schools in neighborhoods that they felt were unsafe. Safety was an issue for Mrs. Paiva as well. Even though she could drive, she attended meetings at her daughter's school only when they were offered during the day because she, too, felt that the school was in an unsafe area. At the time of the interviews, Mr. Xavier and Mrs. Duarte were driving their children to school; they made the one-hour trip twice a day. Mrs. Carvalho said that she had done the same for her son when he was younger.

Differences in Involvement for Parents of Special-Needs Children

The preceding section documents that participation in special-needs children's education can be very similar to that in the education of nonhandicapped siblings. Many activities are the same no matter what kind of school these children attend. As Mrs. Duarte said:

> My involvement in Carlos's education is about the same as my involvement in my other children's education. Carlos's school offers just about the same opportunities for parents to be involved as my other children's school.

What seemed to be quite different, however, was the intensity of the participation in their special-needs children's education. Many of the participants indicated that they were more involved in the education and all aspects of the lives of their special-needs children. Mrs. Paiva typified this attitude when she said:

> It is different because I am more dedicated to participating in her education. I knew that my other children didn't need me the way Elia needs me. They were able to communicate with me. They were able to tell me if something was going wrong at school. Elia is not able to do that. She tells me things that are happening at school, but I never know if what she says is accurate. It is different also because she has therapy and I have to help her with her therapy at home.

All of the participants in this study, even those whose only experience was with the education of special-needs children, told me they felt that these children's school seemed to offer more meetings than the regular schools. They also said that the school-home communication for their special-needs children was a lot more frequent than for their other children. The parents agreed that there just seemed to be more to learn about special-needs children and their conditions.

Several of the participants reported that as soon as they had recovered from the initial shock of learning that their children had special needs, the first thing they did was to learn all they could about their children's disabilities. The first thing Mrs. Castelo and Mr. and Mrs. Xavier did was to read all they could about their children's handicapping conditions. Many of the other parents learned all they could about their children's disabilities by conferring with physicians, special-education specialists, social workers, and therapists. Mrs. Castelo, Mrs. Tavares, and Mrs. Paiva had joined organizations that dealt with their children's specific disabilities. All of these parents emphasized that they have specific rights and responsibilities. In order to make sure that their children receive an appropriate education and the services to which they are entitled, they recognize that it is incumbent upon them to learn both their children's rights and their own rights.

A unique element was the existence of support groups for some of these parents. In these groups, they were able not only to learn about their children's disabilities and how to cope with them, but also how to deal with their own feelings about having a handicapped child. While only two of the parents, Mrs. Castelo and Mrs. Tavares, participated in these groups, many more told me they often attended workshops that dealt with specific aspects of coping with the needs of a handicapped child. The parents indicated that these workshops and support groups were offered either by the schools or the specialized organizations.

Another important difference, especially for those parents whose children were older, was the question of legal guardianship of their special-needs children after they became 18 years old. Mrs. Paiva exemplified this concern when she said:

> Now that she is over 18, we have to go to a lawyer to set up a guardianship for Elia. Even though we are her parents, we still have to name either me or my husband as her guardian. If Elia needs an operation or something like that, she is not capable of making that decision. If one of us isn't her guardian, that decision would be in the hands of strangers. We don't want that.

For most of these parents, involvement will not stop when their children reach 18 years of age. Many of these children will probably need ongoing therapy and care into adulthood. Mrs. Carvalho was the mother of the oldest special-needs child in this study. Her son Quim had already left school and was attending a sheltered workshop:

> I'm still involved in Quim's education. I want to know what he is doing at the workshop, and I make sure he is active in certain organizations. I'm still very involved. I always will be.

Attitudes toward Involvement

In this section, parental attitudes toward involvement in their special-needs children's education will be looked at from different points of view. The parents in this study expressed opinions not only about their own participation but also about involvement by other Portuguese-speaking parents. During the course of my research, I had the opportunity to speak with several Portuguese-speaking professionals. They, too, had insights and opinions about various aspects of parental involvement in the Portuguese-speaking community.

The Parents on Their Own Involvement

Almost all the parents in this study mentioned that they loved being involved and wanted to be involved in their children's education. What seemed to be a very important aspect of these parents's attitudes toward their involvement was how they thought their children felt about that involvement. These parents said that they thought their children were glad their parents were involved. They also felt that being involved showed their children that they cared about them and would always be there for them. Many of these parents were also of the opinion that children whose parents participated in their education did better in school and made greater progress than those children whose parents did not participate. They mentioned that this was particularly true for special-needs children. Mrs. Davila echoed the almost unanimous opinion of these participants when she said:

> It is very important to be involved in your child's education, especially when you have a handicapped child. If we are not involved, they won't do anything. They will be passive and uninterested in the world and people around them. If all children, including handicapped children, had the support of both their parents, they would do much better and they would achieve more. We as parents must be involved in all phases of our children's lives, whether they are handicapped or not. We should be involved in their education as well as at home.

Most of the parents stated that home and school both played important roles in their children's education. They believed that there should be a reciprocal relationship between the home and the school with the lessons learned in one place being reinforced by the other. Although all the participants stated that involvement in the school was important, almost all of them expressed the opinion that the most important involvement in their children's education took place in the home because they felt that it was there that the most important lessons were learned. Mr. Xavier spoke about this:

> I think that involvement has several levels. The first level is the home. I think that it is up to the parents to educate their children. We have to teach our children about religion, morals, and how to behave appropriately. I also teach that in church. Religion at church must be something that is a complement of the things you learn at home. The schools teach children academics, but at home they learn how to behave, and that is where they learn who they are. I think that parental involvement in their children's education starts at home.

Several of the participants expressed the view that by being involved in their children's education they were able to be better informed about what was being done for their children. Mrs. Carvalho summed up this attitude when she said, "By participating in Quim's education, I found that I learned to understand what he was learning and why he was learning it." Some of the parents also added that they felt this involvement helped their relationship with their special-needs children because it brought them closer together. Mrs. Gomes seemed to speak for these parents when she said:

> I'm not only involved with my daughter, but she is also involved with me and my life. We care about each other. I help her, and she helps me. I think we should always be available for our children and be involved in everything they are doing.

I was left with the strong impression that most of these participants felt that involvement in their children's education was a lifelong commitment. Mrs. Duarte said:

> Parental involvement to me is almost indispensable. From the moment that your child is born, you as a parent have a responsibility. Our involvement starts at home.

The Parents on the Involvement of Others

As members of the Portuguese-speaking community, these participants voiced their views that other such parents were little involved in their communities. There seemed to be a high degree of agreement among these participants about the reasons for this perceived lack of participation.

All of the parents said that it was not in the Portuguese tradition to participate in schools. Most of them also cited limited knowledge of English and the need to work long hours as reasons that most Portuguese-speaking parents gave for not being involved in their children's education. Mrs. Dias's opinion was typical of all these participants when she spoke about parental involvement in the Portuguese-speaking community:

> I think that it is very hard for the Portuguese parents to be involved. They don't know the language, and they always have to take someone with them to meetings to interpret for them. Also, we are not used to getting involved in the school. We go to the school only if the teacher needs to talk to us. The Portuguese parents are much more involved at home doing the things that parents do, like taking care of the children, teaching them to have respect for others, and how to live with each other. . . . We don't have parental involvement in Portugal. We don't have that tradition.
>
> I think that parental involvement is important because you always know what is going on at school with your child, but I don't have much time to be involved and the other parents don't either. We just have time to work and that's all.

Mr. Xavier linked this lack of a tradition of parental involvement in their children's education to a general lack of a tradition of participation in any type of "political" activity in general. He went on to explain:

> The Portuguese were taught that politics was a dangerous thing and they associate parental involvement with politics, so they don't get involved because they are afraid to do so.

Mrs. Gomes also mentioned that she felt that lack of involvement was linked to the fact that most of the Portuguese do not vote. Mrs. Duarte, who was very involved in community activities, expressed her frustration about the lack of parental involvement by the Portuguese. She indicated that the Portuguese were often shortchanged by "the system" because of this.

Several of the other participants criticized the Portuguese parents for their lack of involvement. Mrs. Castelo, Mrs. Paiva, and Mrs. Carvalho all said they felt that the reasons given by many of the Portuguese parents for not being involved in their children's education were just excuses. They mentioned that most of the schools now had someone who interpreted for those parents who did not speak English well, so that not knowing the language was no longer a barrier to participation. In their opinion, many of the Portuguese parents could make the time to be involved in their children's education if they were really interested. The parents who held this opinion also felt that it was important for the schools to reach out to the parents in order to let them know the importance of parental involvement in general and to inform the parents about their rights as parents of special-needs children. These same participants indicated it would be helpful to have an advocate for the Portuguese parents who could motivate them to become more involved and help them to better understand their rights.

Other participants brought up what they felt were different aspects of the attitudes that influenced parental involvement in the Portuguese community. Mrs. Paiva, for example, saw the same parents participating, and she felt that those parents who really needed to participate were never there. When it came to special education, Mrs. Davila felt that many Portuguese parents were ashamed of their handicapped children and, therefore, did not become involved in their education.

Mrs. Tavares, who was both a parent of a special-needs child and a special-education professional, combined many of the attitudes of both parents and professionals. She felt that the Portuguese parents were not knowledgeable about their rights and that an advocate might help them become more so. She said she understood the pressures that kept many of the Portuguese parents from being involved, and at the same time, she criticized many of the Portuguese parents for not making their children's education one of their main priorities.

For herself, she felt parent participation was important:

> To me it is a natural thing to be involved. It is my profession. I think with my child, parental involvement is essential. Not only in his case, but with any child. I say that from the professional point of view as well as personal. The more involved you are, the more receptive the child is going to be. . . . If you are aware of what is going on, you are there to support him emotionally and academically. . . . Parental involvement has a positive effect on him and also on the children I had in school whose parents were involved.

She also thought that many of the Portuguese parents felt that if their children were in special education they must be "retarded," and any effort to encourage them would be wasted because these children could not understand anything. Mrs. Tavares herself spoke for many when she indicated that she was not as involved as she would like to be and she should do more. It was my impression, however, that all of the participants in this study were extremely involved in their children's education. I could not imagine how some of them could do more than they were already doing.

What the Educators Said

In my search for parents to be participants in this study, I came into contact with several, mainly Portuguese-speaking, professionals--teachers, school administrators, and social workers--who worked mainly but not exclusively in the Portuguese-speaking community. They, too, shared insights and gave opinions about parental attitudes in the Portuguese community, in particular about attitudes toward parental involvement. These people mentioned that there was not much parental involvement in Portugal and that outside the big cities there were almost no services for special-needs children. They felt that if the Portuguese parents were better informed about what special education is and about the role of parents in it, perhaps more could be done for their special-needs children. Mrs. Dutra, a bilingual/special-education teacher, expressed opinions that I felt were representative of those held by most of these professionals:

> I think that the problem with the Portuguese parents is that they are not informed about special education. They don't know what it is. When they find out that their child needs to be in a special class, they are scared because they think that special education is only for severely handicapped children.
>
> It is very hard to convince these parents that special education can help their child. We don't really have special education in Portugal, so when a child can't do well in a regular environment, parents just don't send their children to school. I think that parents need to be

> informed about special education because the Portuguese parents are always willing to do anything for their children.
>
> It is very hard to classify a Portuguese child to put him/her in special education because parents just don't know what special education is. Also, because these parents feel ashamed when they find out that their child needs special education. . . . It is very hard to get the Portuguese parents to sign any papers for special education because they are very reluctant to sign anything. If these parents were informed about special education, we could help many more children, but they need to be informed. Maybe then they would be more involved.

When talking about the attitudes of other parents, several of the participants in this study agreed with the professionals that for Portuguese parents having a child in special education is looked upon as a stigma and that the Portuguese are reluctant to admit that they have a handicapped child and, therefore, are reluctant to participate in that child's education. When it came to their own children, however, I had the impression that most of the participants did not see having a child in special education as a stigma. None seemed reluctant to be involved in a child's education. The attitudes held by these participants regarding parental involvement seemed to be quite different from those that they and the professionals attributed to Portuguese parents as a whole or to other parents in their community.

The school personnel perceived themselves as reaching out to parents. They believed that parents should be more assertive in seeking out the help that the children need. It seemed possible that this was an impasse for cultural reasons. As we have noted, some of the Portuguese parents claimed to be accustomed to government agencies taking greater initiative and being more directive.

Differing Roles of Wives and Husbands

At first I believed that the participants presented a "traditional" scenario: the husband going out to work and the wife staying home taking care of the children and participating in their education. This was in most cases an oversimplification and in at least one case not true. Only one of the participants reported that her husband was not involved at all in their children's education. Some of the participants did say that their husbands considered attendance at school functions "a woman's job." These same parents told me that their husbands were involved as much as they could be, but the involvement was at home, with therapies and family outings. One husband, because he was disabled and unable to work, ran the household, and others watched the children while their wives attended school meetings.

Both of the Paivas and both of the Xaviers always went to meetings. Not only did Mr. Duarte attend meetings, he also did a lot for the school. Mr. Carvalho was not involved in school but was active in involving his son in community events. The mothers of the three oldest children in the study said that their husbands had been very active in their children's education when the children were younger. Mrs. Davila, Mrs. Castelo, and Mrs. Tavares (who had the youngest children) said that although it was they who attended most of the meetings and conferences at their children's school, their husbands wanted to be informed about what was going on in their children's education and often participated at home.

Mr. Xavier explained that because of his flexible schedule, he had more time than his wife to devote to involvement in their son's education. Even though he was more involved in his son's school, his wife also participated at school, and they were both very involved at home. Most of these participants did not talk of gender issues in involvement in their children's education. The extent of involvement appeared to be mainly a matter of who had more time. As we have seen, however, in almost all these families, it was the woman who was perceived as having more time.

What Schools Can Do to Facilitate Involvement

When asked what could be done to increase parental involvement in their children's education, not just their own but also that of other parents, these participants responded with a variety of suggestions. The most common of these was for some place, either a support group in the schools or a separate center, where the parents could get together with other parents and their children. Some of the participants suggested that the parents themselves should have a strong voice in the running of these groups and centers and that they would offer not only the opportunity for parents and children to get to know one another but also offer such diverse services as English-as-Second-Language classes, parenting workshops, discussion groups, and a sibling support group. Mrs. Tavares touched on several points mentioned by other parents when she said:

> Another thing would be to have more things locally for parents. Have them available so that the parents are able to attend conferences and attend meetings in different neighborhoods so that they can pick where they want to go. Another thing that we could have is a speaker in the parents' native language. We don't have that, so a lot of the Portuguese parents don't go anywhere because they are not bilingual. If it is not offered in Portuguese, they don't go. Also, there are not very many professionals who are bilingual. We should have more professionals who are bilingual.

Other suggestions included providing transportation so that those parents who could not drive would be able to attend activities at their children's schools. Other participants suggested that more activities for parents be held in the evenings and especially on weekends so that working parents would not have to take time off from their jobs in order to participate.

A few of the participants suggested that the medical facilities at their special-needs children's schools be expanded to include doctors and dentists who could provide more comprehensive medical care for the special-needs children. These same parents said that they would like to see greater cooperation among the social-service agencies, especially the boards of education and the schools, in order to deliver more and better services to the special-needs children. Several of the parents said that the schools should make more of an effort to reach out to the Portuguese-speaking parents, especially to teach them what parental involvement is and that in this country it is considered important for them to be involved in their children's education.

Many of the participants expressed a wish for something that was beyond the scope of the schools to provide--more time to accommodate the often conflicting demands of home, family, work, and school. In this way, they said they could be even more involved in all aspects of their children's education.

Thematic Discussion

Theme 1. Involvement in the education of my child with special needs consumes far more time than involvement in the education of my other children.

Previous researchers have indicated the minimal involvement by LEP and bilingual parents in special education (Baca & Cervantes, 1989; Cerrasquello, 1990). They attribute this in large part to a lack of understanding of their rights and responsibilities on the part of the parents. However, I found that the parents in this study were quite involved in their children's education. Many of the parents said that even though they felt that their involvement in their handicapped children's education was not much different from their involvement in their other children's education, it was much more time-consuming. They indicated that their special-needs children's schools had more frequent meetings than other schools. However, I found that the involvement of most of these parents took place in the home. It was here that the difference between their involvement in the education and lives of their special-needs children and their other children became most apparent.

Once these parents realized and accepted the fact that their children had a handicapping condition, many of them decided to dedicate themselves to meeting the needs of these children. This decision took the form of their being more involved in the lives and education of these children. These parents made this decision because they felt that their children with special needs needed them more than their other children. They reported that the level of involvement in all aspects of these children's lives was much more intense than would be appropriate or healthy under normal circumstances. All the parents detailed the kinds of special help and attention that these special-needs children needed. Almost all of these children required special care and therapy that began in infancy and would continue into adulthood. These parents's involvement in their special-needs children was more time-consuming because there was so much more to do. They had to learn about their children's disabilities and often had to work with their children and perform therapy. Most had to feed, dress, and toilet them because these children could not do it on their own. These facts color the kinds of involvement of these parents in all aspects of the children's lives and education.

Nieto (1992a) speaks of the need to expand the definition of parent involvement beyond the more traditional school-related activities. In a talk at Teachers College (1992b), Nieto specifically referred to the day-to-day activities related to the care of children as an important part of parent involvement in their children's education. Epstein (1987-1988) specifically includes this type of day-to-day care for a child among her five types of parent involvement. Kirk, Gallagher, and Anastasiow (1993) make mention of the difficulty experienced by many parents when it comes to caring for their handicapped children. The authors refer specifically to problems associated with dressing and feeding these children. However, these authors see this day-to-day care not so much as involvement but as a responsibility that often weighs on families and must be dealt with sympathetically by professionals. This day-to-day care is seen by the parents in this study not only as a responsibility but also as an important aspect of their participation in their special-needs children's lives and education. Even though their involvement at home was very time-consuming, these parents were involved in school activities as well, as will be seen in the following sections.

Theme 2. We have to ask for what we want and fight for our children. Lacking proficiency in English makes it more difficult for us to understand the school system and learn how to procure the services to which our children are entitled.

All the parents in this study were of the opinion that the special-education services their children received in this country were far superior to those that would be available to them in Portugal or Brazil. This was true both of those parents whose children were born here and of those whose children were born in Portugal and who came to this country because of their special-needs children. However, those parents who came here because of the better services all felt that services were easier to obtain in Portugal. They noted that in Portugal when one had a child with a handicapping condition, services seemed to flow to that child almost automatically. It seemed that these parents were more compliant with and willing to accept the decisions of "the system" when it came to their nonhandicapped children. However, almost all the parents felt that they had to be advocates for their special-needs children in order that these children could receive the services they needed. It was not always clear, however, which of these services were medical rather than educational, to the extent that these can be distinguished for children with special needs. For example, Mrs. Gomes referred to diapers and braces, and Mrs. Davila to physical therapy.

All the parents reported that dealing with the special-education system in this country was quite a struggle for them. Unlike the parental attitude described by Carrasquilo (1990), most of these parents seemed quite well informed about the educational system, their rights, and the services available to their children. They stated, however, that it was necessary to keep after the professionals all the time in order to get the information they needed about their children's education. Even Mrs. Tavares stated that were she not an insider, she would get the same runaround from professionals as "all the other parents."

Harry (1992b) also stated that parents who are from a different cultural and linguistic background are at a greater disadvantage when dealing with the educational system. It is hardly surprising, then, that the parents in this study who were least proficient in English were the ones who had the least knowledge of the educational system and their rights. These parents--Mrs. Gomes, Mrs. Dias, and Mrs. Davila in particular--reported that when dealing with the special-education system, looking for services, and dealing with professionals, they had to be accompanied by another parent, most often Mrs. Duarte, who spoke English and was more familiar with the workings of the special-education system. Mrs. Dias often relied on her older daughter to act as an interpreter.

Baca and Cervantes (1989) pointed out that the lack of rapport between LEP parents and professionals is exacerbated by the lack of personnel educated to deal with these parents in their native language. McCarthy (1991) reported that the main difficulties in communication observed in his study were between Asian parents and professionals, and suggested that the main reasons for this are cultural and linguistic problems. He quoted a parent who complained about the lack of bilingual staff.

McCarthy (1991), in his study of British parents' knowledge of their country's special-education system, found that even though most parents were satisfied with the communication between themselves and professionals, they still wanted more information from teachers. When it came to contacts with professionals other than teachers, McCarthy suggested that there needs to be much more communication. He cited a pair of parents who felt that were they not social-service professionals, they would have a hard time understanding "the jargon." Hardman et al. (1993) noted that many professionals lack the skills and training to give parents information about their children's exceptionality and to establish a satisfactory relationship with the children and their families.

Baca and Cervantes (1989) and Carrasquillo (1990) emphasized that professionals need to give adequate information to parents, especially LEP parents, about their rights and the services available to their children. Correa (1989) argued that, especially in the case of LEP parents, professionals need to take the extra steps to explain relevant aspects of American culture and the educational system. Seligman and Darling (1989) reported that such factors as the ethnic, racial, educational, religious, social, and economic backgrounds of both the parents and the professionals should be taken into account in order for parents and professionals to work together. They say that these factors play an important role in the kind of relationship that parents and professionals will develop.

Theme 3. The schools do a lot to support and involve parents of special-needs children, but we have ideas about how they could do even better.

Most of the parents reported that the special schools their children attended offered a wide range of activities that promoted parent involvement in their children's education. These activities ranged from parent-teacher meetings and having speakers on topics of interest to the parents of special-needs children to activities such as scouting and field trips where parents and children could participate together. On the other hand, some of the parents felt that the schools really offered little more than parent-teacher meetings. However, these parents also stated that they were willing to help out in other ways when they were needed and when their schedules permitted. These parents took advantage in varying degrees of the opportunities for involvement offered by the schools. Some were, of course, more involved than others. Almost all the parents thought that the schools were doing a good job in encouraging parent participation. They particularly liked it that the schools which their children attended all had an "open-door" policy. Under this policy, the parents could make unannounced visits to their children's classrooms.

Nevertheless, all the parents had suggestions for things that schools could do to improve and facilitate parent involvement. Their suggestions were colored by the fact that they are nonnative speakers of English as well as the parents of special-needs children and echoed in some of the more recent bilingual and special-education literature. These suggestions are listed below, followed by citations from the literature, where such exist.

All schools should have parent support groups (Lueder, 1989; Rich, 1988, 1993; Turnbull & Turnbull, 1990). These were available in the schools of some but not all of the families studied.

All schools should have centers that offer a wide range of activities not only for parents but also for the special-needs children and their siblings (Henderson, Marburger, & Ooms, 1986; Hollfield, 1993; Shurr, 1993). None of the participants reported such centers now existing in their children's school.

Classes should be offered in parent education or parenting skills (Correa, 1989; Violand-Sanchez et al., 1991). Mrs. Tavares reported that parenting skills were sometimes introduced as part of the early intervention program in which her son was enrolled.

Child care should be provided so that parents can attend meetings (Correa, 1989; Ensle, 1992; Violand-Sanchez, 1991). Such care was available for the children and siblings in the programs and school attended by Bruno Tavares.

Meetings should be scheduled at times convenient for working parents and transportation provided for those who need it (Coelho, 1994; Correa, 1989; Ensle, 1992). The school of two of the families studied here did have meetings both during the day and again in the evening.

Bilingual interpreters, translators, and liaisons should be trained from the community and made available to those who need them (Coelho, 1994; Correa, 1989; Ensle, 1992; Harry, 1992c;

Violand-Sanchez et al., 1991). Although some of the schools in the community did have staff members available who could translate, there were none in those schools that served only special-needs children. In fact, some of these participants accompanied other parents as translators, and other participants took family members with them to serve as translators.

ESL classes should be made available at centers in the schools (Coelho, 1994; Ensle, 1992). Some researchers (Correa, 1989; Ensle, 1992) also suggested that the schools develop programs that will help LEP parents become more comfortable with American culture and the educational system. This service was not available at the schools of any of these participants.

Special schools should have medical and dental facilities on the premises to serve their children who, the parents said, had greater need for these services than nonhandicapped children. No such facilities were available for any of these families.

CHAPTER VII

SUMMARY, IMPLICATIONS FOR PRACTICE, REFLECTIONS ON METHOD, AND SUGGESTIONS FOR FUTURE RESEARCH

Summary

My purpose in this study was to better understand the involvement of Portuguese-speaking parents in the education of their children with special needs. The literature that deals specifically with parent involvement in bilingual/special-education settings is not comprehensive. There are several studies that are limited to documenting the attitudes about parent involvement of various ethnic groups, but only a few of these studies explore the parents' experiences with involvement or inquire into their wishes. The extant studies cover a number of ethnic groups, but to date I have not located any studies of the Portuguese-speaking population. More particularly, no studies have been located on the involvement of Portuguese-speaking parents of bilingual/special-education students.

This study was designed within the qualitative paradigm, which is particularly appropriate for examining the research question and subquestions. My overall questions were, "How do Portuguese-speaking parents of special-needs children say they want to be involved in their children's education?" and "What are their expressed feelings about parent involvement?" Participants in this study were foreign-born Portuguese-speaking parents who had at least one child in special education. Data were collected through a series of ethnographic interviews with a parent or parents from each of nine families. Chapter IV is devoted to profiles of the families who participated in this research project.

Findings were analyzed within two major categories: Chapter V is focused on the special-needs children and their families, and Chapter VI deals with the families' experiences with their children's education. The findings in each of these chapters are summarized and discussed in the form of thematic analysis.

Analysis in Chapter V was organized around five themes. The first theme was: "Having a handicapped child was a tremendous adjustment for our family." Shock at learning they had a handicapped child was the first reaction of most of the parents in this study. They reported that their lives were turned upside down almost overnight. In order to cope with this shock and to get the best treatment for their children, some of the parents left good jobs in Portugal. Most of the parents said that their children with special needs became the focus of their lives and energies.

Theme 2 stated: "I could not make the doctors listen to me when I told them there was something wrong with my baby." The mothers whose children were not diagnosed as having handicapping conditions at birth or soon thereafter often noticed that there was something not quite right with their children long before the doctors did. The doctors often reacted to their concerns by telling these parents that there was nothing wrong with their children and that perhaps they were just slow in developing. Because of this, the parents often felt that the doctors dismissed their perceptions and did not listen to them, a finding that is confirmed in the literature.

Theme 3 stated: "My special-needs child requires a lot of extra help and attention." The parents said that their special-needs child needed more help than their other children, even if they felt that they treated all their children the same. Although caring for their special-needs child was often stressful, many of the parents said it was a source of great satisfaction to them. Mothers were most often responsible for caring for these children, although in some cases fathers or siblings assumed most of the care-giving tasks. Most of the parents of older handicapped children reported that their children still required much care, and all of the parents saw care for these children as a lifelong commitment.

A salient finding discussed under Theme 4 was: "The learning problems of these children have not prevented them from acquiring a second language." The children in this study exhibited the same fluency in their second language as they did in their first. Some of them appeared more interested in their first language, Portuguese, and spoke it better than their nonhandicapped siblings, while still being fluent in their second language. As their siblings learned the second language, they sometimes tended to ignore or lose their first language. The special-needs children in this study were not only able to learn a second language but to maintain their first. Although there is little written about second-language acquisition by children who have deficiencies in their first language, what has been written states that children with handicapping conditions can learn a second language without detriment. The experiences of the children in this study bear this out and indicate that handicapped children may have greater language ability than is commonly assumed.

A few of the parents in this study experienced the questioning of religious values that is reported in the literature when they learned they had a child with special needs (Turnbull & Turnbull, 1990). However, this reaction, when it did occur, was relatively short-lived. Many of the parents came to feel, as Theme 5 stated, that "This child has been a gift from God." Some of the parents also reported that their special-needs child helped to bring their family closer together. The strong bond between mothers and their special-needs children that is reported in the literature was present among this group.

Themes discussed in Chapter VI explored various aspects of the experiences of the families with the school systems and of their involvement in their children's education. These experiences were colored by their proficiency in English and their minority-group status, as discussed under Theme 1:

> We have to ask for what we want and fight for our children. Lacking proficiency in English makes it more difficult for us to understand the school system and know how to procure the services to which our children are entitled.

These parents stated that services for their special-needs children are better here than in Portugal or Brazil. Those parents who had experience with the special-education systems, both in the United states and in Portugal, said that services were easier to obtain in Portugal. In the United States, they often had to seek appropriate services. Dealing with the special-education system was a struggle for them. The literature reports that minority parents, especially LEP parents, experience difficulties with the special-education system because of their linguistic and cultural differences. The parents in this study who were the least proficient in English had the greatest difficulties with the system and were the least knowledgeable about their children's rights and the services available to them. The literature also points out that various factors, including the race, culture, religion, and language of both the parents and the professionals, need to be taken into consideration if they are to work together effectively.

The second theme was: "Involvement in the education of my child with special needs consumes far more time than involvement in the education of my other children." Although the literature has noted that involvement by LEP parents in special-education programs is minimal, most of these parents, whether LEP or not, were very involved. These parents stated that much of their involvement took place in the home, and they had dedicated themselves to being involved with these children because the children needed them so much. These parents's involvement was more time-consuming than involvement with their other children's education because there was so much to do: learn about the disability; perform therapy; and help children dress, bathe, or feed themselves. The schools of their special-needs children had more meetings than the other children's schools, and they often needed more frequent contact with school personnel.

Some researchers have talked of expanding the concept of parent involvement to include the day-to-day involvement in the children's lives. Others, however, see this type of care as a basic responsibility of parents rather than as part of involvement in their education. The parents in this study not only recognized day-to-day care as their responsibility but also as very important involvement in their children's lives and education.

Theme 3 was focused on the parents's perception that: "The schools do a lot to support and involve parents of special-needs children, but we have ideas about how they could do even better." Although most of these parents were happy with what their children's schools had to offer in terms of parent involvement activities, they nevertheless had suggestions for ways that schools could increase parent involvement. Their suggestions were colored by the fact that they were both nonnative speakers of English and parents of children with special needs. The parents suggested the establishment of support groups and parent centers. Activities suggested for these centers included parenting classes, ESL classes, and day care. They thought that the most important function of these centers would be to provide a place for parents and children to get to know one another. It was also considered important that these centers provide these services in the parents' native language to help those parents who did not speak English. Another suggestion made by the parents was that all special-education schools should have medical and dental facilities to serve the children because children who have handicapping conditions need more medical care than other children.

Implications for Practice

In the preceding two chapters, discussion of particular findings has been presented in the form of thematic analyses at the ends of the chapters. The discussion in this chapter is organized under two metathemes and addresses salient implications that the findings have for education. This discussion arises from the findings of the present study that were limited to the stories of nine families. What is said here will be pertinent to other such families only if these findings hold for them. In my experience in this field and from other literature, that may well be so.

Metatheme 1. What these children can do is immensely more important than what they cannot do.

The education of children with disabilities should include a great deal more than just strengthening those areas in which these children have obvious deficiencies. Special-needs children, as all children, need to be exposed to all sorts of stimuli, activities, subjects, and experiences that they would not necessarily meet in their daily lives. These children need to be challenged and encouraged to reach their full potential. This is not to say that all special-education programs do not challenge their students. Many of the participants in this study, however, did not think that their children were sufficiently challenged in many areas. If these children, who were in reasonably satisfactory special-education programs, were not being challenged, can we not infer that many other children are not being challenged? With at least two thirds of handicapped adults unemployed, it is legitimate to question what the goals of special education really are. It certainly seems that even though a great deal of effort and money are being expended on special education, the results are often disappointing.

An important first step in giving these children a more meaningful life would be to abandon or at least deemphasize the deficit model when educating them. Instead of concentrating on those areas where these children are weak, special educators should also try to increase skills where these children have shown interest and aptitude, just as would be done for other children. Teachers could certainly build skills where these children are deficient by using those talents and abilities that the children already have. Professionals need to look a lot more closely at the areas where these children are strong. For instance, a child who understands and speaks two languages, as most of the children in this study do, is obviously capable of learning a great deal. Yet the schools seemed to pay little or no attention to this skill. It seems that special-education teachers need to raise their expectations of what these children can do.

As was noted earlier, almost all the parents expressed a general satisfaction with their children's programs. However, the parents of the older children reported that, although their children were encouraged to learn and reach their maximum potential, what they were encouraged to learn very often did not take into account the children's individual talents and abilities. These parents felt that learning such basic skills as self-care and how to get along with others was important because they wanted their children to be as independent and self-sufficient as possible. On the other hand, the parents also wanted their children to have a life that was as fulfilling and satisfying as possible. It was this aspect of their children's education and placement that many of the parents of the older children questioned. According to these parents, their children had talents, interests, and abilities that were well beyond the practical skills that the special-education programs emphasized, and in many cases these talents and interests were being overlooked by the special-education professionals. They believed that if the schools paid more attention to their children's abilities and interests, these children would have a greater opportunity to have more fulfilling lives.

At the time of this study, only one of the older children had graduated from school and was working at a sheltered workshop. His mother felt that what her son was doing at the workshop was just busywork that did not interest him and made no use of his interpersonal communication skills that she felt were her son's great strength. She said that if the school, which she felt was very good, had placed more emphasis on her son's abilities, they would have been able to find him more fulfilling employment. Another parent, while again generally happy with her son's program, criticized the fact that he was learning much needed daily-living and survival skills at the expense of, rather than in addition to, academic subjects such as reading, writing, and math. She reported that her son was starting to forget the skills in these areas that he had learned at his previous school.

Mrs. Paiva expressed the concerns of most of these parents when she said that she realized that the adult center that her daughter would soon be attending had a program designed to keep her daughter "busy" rather than providing her with any type of employment. She said that almost anything was preferable to having her daughter stay home to watch videos. Concerns such as hers are certainly legitimate in view of the fact that only about one third of the adults with disabilities are employed (Hardman et al., 1993; Kirk, Gallagher, & Anastasiow, 1993).

What can be done to increase the number of handicapped adults who are not just kept busy but who have at least the prospect of some kind of meaningful employment? When looking at the goal of special education, one would hope it would be to prepare the children for as much independence as possible when they become adults. This preparation must begin well before the children near adulthood. When preparing the children for their transition from school to the rest of their lives, schools need to work closely with agencies that provide services for handicapped adults, make contact with the local business community so that they can inform parents about the types of employment that would be available for their children, and involve parents in all aspects of their children's education. This is especially important when children make the transition from school to the community. Educators need to realize that what these children do after they leave school will be the longer and more important part of their lives. To help make adulthood as meaningful as possible, special educators must at least try to involve these children in activities or employment that will take into account their special talents and interests. Sending these children out to do busywork or, worse, letting them sit at home in front of the television when they can do more is a waste not only of years of special education but also of these children's lives.

Metatheme 2. Parents of such children need to be viewed as very rich resources.

It is widely accepted that parents are their children's first and most important teachers. Parents also know their children better than anyone else. Nevertheless, as was documented in Chapter V, doctors often dismissed as irrelevant these parents' insights and perceptions about their own children. For a long time now, other researchers (Alexander, 1982) have realized that professionals usually regard parents of special-needs children as in need of information rather than rich sources of information.

Not only did the parents in this study have a great deal of knowledge about their own children, but, as speakers of another language and members of another culture, they had a great deal of knowledge about their own culture in addition to the skills of their various professions and occupations. From what the parents related both directly and indirectly, it appeared that very often the special-education system as a whole did not consider them as important resources in their children's education. On the contrary, it seemed that at times educators and administrators had an almost adversarial relationship with the parents.

As we have seen, most of these parents were quite involved in their special-needs children's education. However, with few exceptions, this involvement did not extend beyond the traditional "bake sale" variety where parents were encouraged to take part in fund-raising activities and help out around the school. In only two cases did parents mention that their suggestions regarding teaching strategies were actually put into effect or that they were asked to speak to other parents on issues that might be of concern to them. In this latter case, the parent was also a professional in the field. On the other hand, one of the parents complained that even when the educators asked for his opinion on matters concerning his child's education, his opinion was then ignored. This same parent also complained of the unresponsiveness of the oversight agencies when he sought solutions for problems his child was having.

Another parent, who had been a nurse in Portugal, was keenly aware of the importance of hygiene for her own special-needs child. She reported that when she offered to talk about hygiene at her child's school, she was immediately turned down. This parent said that she did not know exactly why she had been turned down, but felt that her limited English skills were the reason. It has been my experience that when someone does not speak English well, or even just has a heavy accent, many people in this country assume that the person cannot possibly have a profession, an education, or even a valid insight. American society in general, and we as educators in particular, must learn to do more than just pay lip service to the idea of valuing the talents and contributions of immigrants.

All parents are important sources of information both to educators and to other parents. The parents in this study spent a great deal of time with their children and could thus give educators important information and insights about their children's behavior and development. These parents could also give important information on their children's learning styles and could suggest strategies that might be helpful in working with their children. This is especially important because these families come from a culturally and linguistically diverse background. Their worldview may be different from that of mainstream United States. According to the parents in this study and my own experience, the Portuguese, and the Brazilians with whom they share a cultural heritage, have a worldview that sees the family not only as the basic cultural unit, but also as the first and most important source of support for the individual. They come from a tradition that does not question authority, but rather defers to it. This affects their views on education in general and on parent involvement in particular. For these parents, teachers assume the primary responsibility for and authority over their children in school. The teacher is seen as someone in authority who should be obeyed and not questioned. If professionals do not know anything about these parents's culture, they could easily misinterpret the parents' respect and deference as lack of interest or concern with their children's education.

Beyond insights into their own culture, these parents have insights and information about child-rearing practices that might be of interest both to professionals and to other parents. Parents can serve as an important support system for one another. They can help one another with the problems and stress of having a special-needs child. Parents who have experience dealing with special-needs children and their education can guide those parents who do not and are still struggling to come to terms with their lives as parents of special-needs children. Furthermore, because these parents do not have a tradition of parent involvement in their children's education, those parents who are involved can in turn encourage other parents to become involved. Parents are ideally suited to teach other parents of the same cultural background about the American education system and the importance placed on their involvement in their children's education. Since these parents come from a culture where deference to authority is the norm, educators need to find strategies that encourage them to speak their minds on matters concerning their children. To make use of parents as a resource and get them involved in their children's education, educators need to listen to parents as much as they talk to them. Parents have a lot to say if only professionals would listen to them.

Parent involvement activities should not only be initiated by schools, but also by parents. We need to empower parents and let them know that what they have to offer is important in helping their children. We should ask parents how they want to be involved. Parents need to feel that what they say is valuable, listened to, and taken into consideration. Beyond this, parents need to see some of their suggestions put into practice and to help assess these as part of a professional dialogue.

Reflections on Method

Gaining Entry

If there is one thing that I have learned about conducting qualitative research, it is that it will probably take longer than one expects. After I had gained entry and was making plans to conduct the interviews, I developed a tentative schedule of twelve weeks during which I thought I would be able to conduct all the interviews. In fact, it was 16 weeks before I finished because most of the parents worked and had responsibilities to their families and communities. I soon learned that we as researchers must alter our schedules to accommodate those of the participants. When I first realized that I would not be able to keep my original interview time table, I became quite discouraged.

As a matter of fact, this was not the only aspect of doing this type of research that I found discouraging and/or frustrating. When I first contacted those professionals with whom I had already established a relationship, they told me that I would probably have trouble finding parents who would be willing to talk about their special-needs children and their involvement in their education. It was the opinion of almost all of these professionals that the Portuguese-speaking parents felt that having a special-needs child was mainly a family matter to be discussed only with those professionals who were directly involved with their children. My contacts led me to believe that the parents I hoped to interview would be suspicious of an outsider prying into their affairs.

After hearing this almost unanimously from the people who worked directly with my chosen population, I contemplated changing either the focus of my research or coming up with an entirely new topic. I especially became confused when a Portuguese-speaking professor I knew suggested I should not rely on the educators and administrators but needed to contact the parents directly. I then posted flyers on several community bulletin boards and placed an advertisement in a local Portuguese-language newspaper and got no response at all. My luck changed when I called Mr. Elias, the administrator who had been my first contact in the local school system, and asked in desperation what I could possibly do to attract participants. It was then that he gave me the name of his friend who had a special-needs child and who Mr. Elias thought would be willing to participate in my study. When this parent not only agreed to participate but also gave me the name of another parent who had a special-needs child, things began to "snowball." I eventually located eight of my nine participants by word of mouth from one parent to another.

During this process and throughout the entire course of this research project, patience proved to be a great virtue indeed. Every time I was told that someone was out and I had to call back, and every time I had to repeat the same explanations of what my planned research was and why I wanted to do it, I had to keep in mind that it was a necessary and inevitable part of conducting this type of research. I also had to learn how to be philosophical about those contacts that went nowhere and to focus on those contacts that seemed to be leading me closer to willing participants. As I got to talk to potential participants, it became obvious to me that their numbers would not be great. It then became very important to keep in touch with these potential participants in order to get them to meet with me and, I hoped, to agree to participate in my study.

It was difficult when parents who had agreed to be participants either did not show up for appointments or kept me hanging for long periods of time from one interview to the next. With a couple of the parents, I had to keep calling to try to make appointments, and I was never sure that they would not pull out until I saw them for the third and final interview.

Interviewing

When conducting an ethnographic interview, it is important for the researcher to establish rapport with the participants. The first and I think most obvious way I was able to establish this rapport was by speaking to them in their native language. I believe that if I had gone into this study speaking only English probably half of my participants would not have participated if for no other reason than they would not have felt comfortable speaking English. I was also able to establish a greater rapport with these parents because my mother and I had gone through many similar experiences. I had been a special-needs child and my mother, at least in the beginning, had been a LEP parent. Some of the parents were more interested in my background than others. I spent more time talking about my own experiences to those parents, and with others I went on to other topics.

The place where the interviews were conducted was an important factor in making the participants feel at ease. Most of the interviews were conducted in the parents' homes. This helped me to get to know them more intimately and often led me to talk about their homes or neighborhoods during the course of our conversations. Being able to steer the conversation to familiar topics helped us overcome awkward moments. By being in their homes, we were often interrupted during our interviews. I saw those interruptions both as negative and positive. They were negative in that they often distracted us and it was difficult to get back to the questions that I needed to ask. These interruptions, especially those from their children, were positive in that they helped me to see how the children and the participants interacted and thus get a clearer and more complete picture of the participants and their families.

I needed to be flexible when asking my questions, not only to cope with interruptions but also at times to make the questions more understandable to the parents or less emotionally charged. I feel that the first interview with the first participant was rather stiff and mechanical. After I transcribed and read it, I found it did not have the open qualities of a dialogue for which I was striving. As I grew more experienced and confident, the interviews became more free flowing and natural. The parents and I were really having conversations.

When I first undertook this kind of research, I assumed that I would tape-record all of the interviews. There were, however, two participants who would not agree to be taped. I was so afraid that I would not remember enough that I almost did not include them as participants. I decided, however, to trust myself and to go ahead. When I sat down to write up these interviews on the basis of the sketchiest of notes, I was surprised at how much I recalled. It was almost like having a tape recorder in my head--I could actually hear their own words in their own voices. I learned from this experience that as qualitative researchers we have to trust ourselves.

Two of the parents found it so difficult to open up to me and express themselves during our first interview that I thought about not using them as participants. These were also the two parents who would not agree to let me tape the interviews. They became a source of interesting and rich data, however, and I was glad that I persevered.

Some of the parents wanted to talk to me at length about their personal problems, and I found I frequently had to steer our conversation back to the interview questions. Initially, I felt it was wonderful that these parents were able to be so open with me, and trusted me, but it was often frustrating to listen to a litany of their problems when I really wanted answers to my questions. As time went by, however, I came to view these digressions differently. I saw the problems they confided to me as part of the context for the parents' involvement in their children's education, and these insights helped me broaden the focus of the study.

Feelings

There were a few participants who did not make an immediate favorable impression on me. However, I was determined to continue because I needed all the participants. Upon getting to know these particular parents better, I found that my first, unfavorable, impression was mistaken. In fact, in the end, I became very close to all the participants.

Having become close to these parents, I then had to deal with my own feelings of empathy and sadness for them. I had had many experiences similar to those of my participants or their children. When listening to them, I really felt that it was true when they told me they loved talking about their children. At the same time, I sensed a deep sadness in many of the participants. On more than one occasion I was almost overcome by my desire to do something to ease their burden. It was frustrating to know that as a researcher at this point the best I could do was to give them the opportunity to tell their stories.

My feelings were particularly strong while I was rereading my data and writing the profiles. Sometimes I felt sad, sometimes frustrated, sometimes angry for them. With Mrs.

Castelo, I was almost overwhelmed by how much she had to take care of: a family with four children, two of them in special education, and a job. I felt like saying to her, "Isn't there something I can do to help you?"

I felt a real closeness to the Tavares family. I was filled with sadness and compassion because they had lost two of their triplets, and the one that was left was so severely handicapped. Because I felt I had so much in common with them, I had to make a special effort to work toward objectivity. I consciously tried to be fair to their stories, not to mine.

I felt that doing qualitative research, especially interviewing the parents of special-needs children, was emotionally draining, gruelling, and frustrating. It was also a rich and rewarding experience for me. Conducting this research made me more perceptive. I learned to listen to people and accept their points of view. I would gladly conduct this type of study again.

Suggestions for Future Research

A search of recent literature indicates that there are some studies being conducted with culturally and linguistically diverse parents of children with special needs. It appears that most of the studies focus on Hispanic and Asian parents (De León, Ortiz, Sena, & Medina, 1996; Matsuda, 1994). The Portuguese-speaking population has not, however, been the subject of much research. Very little research has been done with the Portuguese in the United States, and even less has been conducted with Brazilians because they are such a recent immigrant group. Also, it is possible that these groups have been largely ignored because relatively few researchers speak Portuguese. In addition, the Brazilians are definitely an "invisible" population because, according to Margolis (1994), among other reasons, there are no distinctively Brazilian residential neighborhoods. Brazilians tend to live in other immigrant communities where they are often submerged in the larger population group. It could benefit educators at all levels to become better acquainted with the culture and educational experiences of the Portuguese-speaking immigrant groups.

More qualitative research is certainly needed with not only Portuguese-speaking but also other culturally diverse populations whose families are involved in special education. During the course of this study, the focus of which was on parent involvement, various other issues were raised by the participants. Researchers need to explore in greater depth the attitudes of these parents and children about disability in general and toward the various special-education programs in particular. Culturally diverse families often have different views about special education and even different ideas as to what constitutes a disability.

Research is also needed on how parents of children with special needs view the transitional programs provided for their older children and their own involvement in these programs. As was noted above, this was a topic of major concern for the parents of older handicapped children in this study.

Another profitable issue for researchers to explore is the social and political implications of keeping these severely challenged children segregated. This is especially important given that IDEA (Individuals with Disabilities Education Act of 1990), formerly PL. 94-142 (The Education of All Handicapped Children Act of 1975), mandates that children with special needs be educated in the least restrictive environment possible. One of my participants, Mrs. Dias, expressed the opinion that although she recognized that her son Nelson needed to be in special education, he would benefit from being in an environment with less severely handicapped children. The question for researchers to explore is whether, or in what ways, it would be of benefit to these children to be in a more normal environment. Another question that could be addressed is whether or not all special-needs children would really benefit from such a policy.

This study shows that most of the participants' special-needs children were equally fluent in both English and Portuguese to the extent of their abilities. On the other hand, most of their siblings either did not speak Portuguese or, if they did, they preferred to speak English. With this in mind, researchers could focus on the language use of these special-needs children and their siblings to investigate the factors that influence these children's abilities and/or desire to learn both Portuguese and English or one language in preference to the other.

Another possible area for research is to compare the attitudes of Portuguese parents in this country toward education and their involvement in their children's education with the attitudes of Portuguese parents in Portugal or Brazil. Another comparison is the attitudes of Portuguese-speaking parents with the attitudes of the majority population. All of the issues that have been presented here could not only be conducted with the Portuguese-speaking population, but also with parents of other ethnic groups. The writings of Nieto (1992a, 1992b) and Swick (1991) and others who advocate education for a multicultural society, as well as this present study, all support the value of such research endeavors. Additional research along these lines would provide insights that could be used to further the empowerment of parents and students of diverse ethnic groups and special needs and lead to a more interactive and inclusive approach to education for all students.

BIBLIOGRAPHY

Alexander, R. N. (1982). The parent role in special education. In R. L. McDowell, G. Adamsen, & F. Wood (Eds.), Teaching emotionally disturbed children (pp. 300-317). Boston: Little Brown.

Allen, P. (1994). When children speak a different language. Day Care and Early Education, 22(1), 38-39.

Baca, L. M., & Cervantes, H. T. (1989). Bilingual special education interface. Columbus, OH: Merrill Publishing Co.

Barquet, N. (1993, January). Parent involvement in American education: A national origin perspective. IDRA Newsletter, XX(1), 6-8.

Bauch, P. A. (1988). Is parent involvement different in private schools? Educational Horizons, 66(2), 78-82.

Becher, R. M. (1984). Parent involvement: A review of research and principles of successful practices. Washington, DC: National Institute of Education.

Becker, H. J., & Epstein, J. L. (1982). Parent involvement: A survey of teacher practices. The Elementary School Journal, 83(2), 85-102.

Beckman, P. J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 88, 150-156.

Bermúdez, A. B. (1993). Teaming with parents to promote educational equality for language minority students. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 175-188). Albany, NY: State University of New York Press.

Bermúdez, A. B., & Marquez, J. A. (1996). An examination of a four-way collaborative to increase parental involvement in the schools. The Journal of Educational Issues of Language Minority Students, 16, 1-16.

Bogdan, R. C. & Biklen, S. K. (1992). Qualitative research for education: An introduction to theory and methods. Boston: Allyn & Bacon.

Brandt, R. (1989, October). On parents and schools: A conversation with Joyce Epstein. Educational Leadership, 47(2), 24-27.

Bransford, J., & Chavez, R. L. (1988). Training for minority language parents: Are we providing what they want or need? In H. S. Garcia & R. L. Chavez, Ethnolinguistic issues in education (Eric Document 316 040).

Cardenas, J. A. (1993). Compatibility in parental involvement. IDRA Newsletter, XX(1), 2.

Careaga, R. (1988, Fall). Parent Involvement: A resource for the education of limited English proficient students. NCBE, 8, 1-2.

Carrasquillo, A. L. (1990). Bilingual special education: The important connection. In A. L. Carrasquillo & R. E. Baecher (Eds.), Teaching the bilingual special education student (pp. 4-23). Norwood, NJ: Ablex.

Carrasquillo, A. L., & Bonilla, M. A. R. (1990). Teaching a second language to limited English proficient learning disabled students. In A. L. Carrasquillo & R. E. Baecher (Eds.), Teaching the bilingual special education student (pp. 67-89). Norwood, NJ: Ablex.

Cassidy, E. (1988). Reaching and involving black parents of handicapped children in their child's education. Final Report, Minority Outreach Project. Lansing, MI: CAUSE, Inc.

Chavkin, N. F. (1989a). Debunking the myth about minority parents. Educational Horizons, 7(4), 119-123.

Chavkin, N. F. (1989b). A multicultural perspective on parent involvement: Implications for policy and practice. Education, 109(3), 276-285.

Chavkin, N. F. (Ed.). (1993). Families and schools in a pluralistic society. Albany, NY: State University of New York Press.

Chavkin, N. F., & Williams, D. L. (1988). Critical issues in teacher training for parent involvement. Educational Horizons, 66(2), 87-89.

Chavkin, N. F., & Williams, D. L. (1993). Minority parents and the elementary school: Attitudes and practices. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 73-83). Albany, NY: State University of New York Press.

Clark, R. M. (1988). Parents as providers of linguistic and social capital. Educational Horizons, 66(2), 93-95.

Cloud, N. (1994). Special education needs of second language students. In F. Genesee (Ed.), Educating second language children: The whole child, the whole curriculum, the whole community (pp. 243-277). New York: Cambridge University Press.

Coelho, E. (1994). Social integration of immigrant and refugee children. In F. Genesee (Ed.), Educating second language children: The whole child, the whole curriculum, the whole community (pp. 301-327). New York: Cambridge University Press.

Comer, J. P. (1986). Parent participation in the schools. Phi Delta Kappan, 67(6), 442-446.

Comer, J. P. (1991, Summer). Parent participation: Fad or function? Educational Horizons, 69(4), 182-188.

Correa, V. I. (1989). Involving culturally diverse families in the educational process. In S. H. Fradd & M. J. Weismantel (Eds.), Meeting the needs of culturally and linguistically different students: A handbook for education, pp. 130-144. Boston: Little, Brown and Company, College-Hill Publication.

Council of Chief State Officers. (1991). Families in school (State Strategies and Policies to Improve Family Involvement in Education). Washington, DC: Author.

Cremin, L. A. (1976). Traditions of American education. New York: Basic Books.

Crespo, O. I., & Lougue, P. (1984). Parent involvement in the education of minority language children: A resource handbook. Rosslyn, VA: Interamerican Research Associates, NCBE.

Cummings, J. (1983, Fall). Bilingualism and special education: Programs and pedagogical issues. Learning Disability Quarterly, 6, 373-386.

Cummins, J. (1991). Empowering minority students: A framework for intervention. In N. Minami & B. P. Kennedy (Eds.), Language issues in literary and bilingual/multicultural education. Harvard Educational Review, 22.

Dauber, S. L., & Epstein, J. L. (1993). Parents' attitudes and practices of involvement in inner-city elementary and middle schools. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 53-71). Albany, NY: State University of New York Press.

Davies, D. (1993). Benefits and barriers to parent involvement: From Portugal to Boston to Liverpool. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 205-216). Albany, NY: State University of New York Press.

De León, J., Ortiz, R., Sena, G., & Medina, C. (1996). Hispanic parent involvement and perspective in the education of the preschool child with developmental disabilities. The Journal of Educational Issues of Language Minority Students, 16, 33-48.

Dornbusch, S. M., & Ritter, P. L. (1988). Parents of high school students: A neglected resource. Educational Horizons, 66(2), 75-77.

Eisenstein, M., & Bodman, J. (1993). Expressing gratitude in American English. In G. Kasper & S. Blum-Kulka (Eds.), Interlanguage pragmatics. New York: Oxford University Press.

Ely, M., Anzul, M., Friedman, T., Garner, D., & Steinmetz, A. M. (1991). Doing qualitative research: Circles within circles. Bristol, PA: Falmer Press.

Ensle, A. L. (1992). Critical elements in parental involvement of culturally and linguistically diverse parents. Bilingual Research Journal, 16(3-4), 141-143.

Epstein, J. L. (1984, Winter). School policy and parent involvement: Research results. Educational Horizons, 62(2), 70-72.

Epstein, J. L. (1986). Parent involvement: Implications for limited English proficient students. In C. Simich-Dudgeon (Ed.), Issues of parent involvement and literacy. Washington, DC: Trinity College.

Epstein, J. L. (1987). What principals should know about parent involvement. Principal, 66(3), 6-9.

Epstein, J. L. (1988). How do we improve programs of parent involvement? Educational Horizons, 66, 58-59.

Gargiulo, R. (1985). Working with parents of exceptional children. Boston: Houghton Mifflin.

Gargiulo, R. M., & Graves, S. B. (1991, Spring). Parental feelings: The forgotten component when working with parents of handicapped preschool children. Childhood Education, 7(3), 176-178.

Gelb, S. (1982). A guide to working with minority language students in special education. State of Washington: Superintendent of Public Instruction.

Gordon, I. (1978). What does research say about the effects of parent involvement on schooling? Paper presented at the Annual Meeting of the Association for Supervision and Curriculum Development.

Graves, S. B., & Gargiulo, R. M. (1993). Strategies for supporting families. Day Care & Early Education, 21(2), 47-48.

Hardman, M. L., Drew, C. J., Egan, M. W., & Wolf, B. (1993). Human exceptionality: Society, school and family. Boston: Allyn & Bacon.

Harry, B. (1992a). Cultural diversity, families and the special education system: Communication and empowerment. New York: Teachers College Press.

Harry, B. (1992b). An ethnographic study of cross-cultural communication with Puerto Rican-American families in the special education system. American Educational Research Journal, 29(3), 471-494.

Harry, B. (1992c). Restructuring the participation of African-American parents in special education. Exceptional Children, 59(2), 123-131.

Harry, B., Torguson, C., Katkavich, J., & Guerrero, M. (1993). Crossing social class and cultural barriers in working with families. Young Children, 46(3), 40-42.

Henderson, A. (Ed.). (1987). The evidence continues to grow: Parent involvement improves student achievement. Washington, DC: National Committee for Citizens in Education.

Henderson, A., Marburger, C. L., & Ooms, T. (1986). *Beyond the bake sale: An educator's guide to working with parents*. Columbia, MD: National Committee for Citizens in Education.

Hogan, J. (1990). *Advocating for children: A parents' guide to reading, writing and learning disabilities*. Hemisphere Publishing Corporation.

Hollifield, J. (1993). The league of schools reaching out: Getting parents going. *Educational Digest*, *58*(8), 9-13.

Honig, A. S. (1979). *Parent involvement in early childhood education*. Washington, DC: National Association for the Education of Young Children.

Hornby, G. (1988). *Fathers of handicapped children*. Unpublished manuscript. University of Hull, England.

Kasper, G., & Blum-Kulka, S. (1993). *Interlanguage pragmatics*. New York: Oxford University Press.

Kirk, S. A., Gallagher, J. J., & Anastasiow, N. J. (1993). *Teaching exceptional children* (7th ed.). Boston: Houghton Mifflin.

Kroth, R. L. (1985). *Communicating with parents of exceptional children: Improving parent-teacher relationships*. Denver: Love Publishing Company.

Leigh, J. (1987). Parenting and the hearing impaired. *Volta Review*, *89*(5), 11-21.

Leitch, M. L., & Tangri, S. S. (1988). Barriers to home-school collaboration. *Educational Horizons*, *66*(2), 70-74.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.

Lindle, J. C. (1989). What do parents want from principals and teachers? *Educational Leadership*, *47*(2), 12-14.

Lueder, D. C. (1989). Tennessee parents were invited to participate--and they did. *Educational Leadership*, *47*(2), 15-17.

Marion, R. L. (1981). *Education, parents and exceptional children*. Rockville, MD: Aspen Systems Corporation.

Margolis, M. L. (1994). *Little Brazil: An ethnography of Brazilian immigrants in New York City*. Princeton, NJ: Princeton University Press.

Matsuda, M. (1994). Working with Asian parents: Some communicatiion strategies. In K. G. Butler (Ed.), Cross-cultural perspectives in language assessment and intervention. Gaithersburg, MD: Aspen.

McCarthy, T. (1991). Children with special education needs: Parents' knowledge of procedures and provisions. British Journal of Special Education, 18(1), Research Supplement, 17-19.

Michael, M. G., Arnold, K. D., Mogliacca, L. A., & Miller, S. (1992). Influences on teachers' attitudes of the parents' role as collaborators. Remedial and Special Education, 13(2), 24-39.

Moles, O. C. (1993). Collaboration between schools and disadvantaged parents: Obstacles and openings. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society. Albany, NY: State University of New York Press.

Navarrette, Y. G. (199[illegible]). Family involvement in a bilingual school. The Journal of Educational Issues of Language Minority Students, 16, 77-84.

New Jersey State Department of Education. (1984). Effective practices for [illegible] bilingual parent involvement [illegible]. Trenton, NJ: New Jersey State Department of Education, Division of Compensatory/Bilingual Education.

Nieto, S. (1985, September-December). Who's afraid of bilingual parents? Bilingual Education Review, 12(3), 179-189.

Nieto, S. (1992a). Affirming diversity: The socialpolitical context of multicultural education. White Plains, NY: Longman.

Nieto, S. (1992b). No, she's not involved: Students' perspectives of parent involvement. Talk given at the Conference on Parent Involvement in the Schooling of Bilingual/Bicultural Student Population, June 29-30.

Nissani, H. (1990, Summer). Early childhood programs for language minority children. Occasional Papers in Bilingual Education, 2. Washington, DC: NCBE.

Ohio State Department of Education. (1984). Manual for encouraging parent-community involvement in bilingual education and English as a second language programs. Columbus, OH: Ohio State Department of Education, Office of Equal Educational Opportunity.

Pap, L. (1981). *The Portuguese-Americans*. Boston: Twayne Publishers.

Patton, M. Q. (1987). *How to use qualitative methods in evaluation*. Newbury Park, CA: Sage Publications.

Pyszkowski, I. S. (1989). Parents as partners in educating the young. *Education*, *109*(3), 286-294.

Ratleff, J. E. (1989). *Instructional strategies for cross-cultural students with special education needs*. Sacramento, CA: Programs, Curriculum and Training Unit. Special Education Division, California State Department of Education. Available from Resources in Special Education, Sacramento, CA

Rich, D. (1988). Bridging the parent gap in education reform. *Educational Horizons*, *66*(2), 90-92.

Rich, D. (1993). Building the bridge to reach minority parents: Education infrastructure supporting success for all children. In N. F. Chavkin (Ed.), *Families and schools in a pluralistic society* (pp. 235-243). Albany, NY: State University of New York Press.

Rintell, E. (1989). That reminds me of a story: The use of language to express emotion by second language learners. In M. R. Eisenstein (Ed.), *The dynamic interlanguage: Empirical studies in language variation* (pp. 237-260). New York: Plenum Press.

Ritter, P. L., Mont-Reynaud, R., & Dornbusch, S. M. (1993). Minority parents and their youths: Concern, encouragement, and support for school achievement. In N. F. Chavkin (Ed.), *Families and schools in a pluralistic society* (pp. 107-119). Albany, NY: State University of New York Press.

Rosado, L. A., & Aaron, E. B. (1991, Winter). Parental involvement: Addressing the educational needs of Hispanic inner-city students. *Journal of Educational Issues of Language Minority Students*, *8*, 23-28.

Rose, H. W. (1987). *Something's wrong with my child*. Springfield, IL: Charles C. Thomas.

Schultz, J. (1987). *Parents and professionals in special education*. Boston: Allyn & Bacon.

Scott-Jones, D. (1988). Families as educators: The transition from informal to formal school learning. *Educational Horizons*, *66*(2), 66-69.

Scott-Jones, D. (1993). Families as educators in a pluralistic society. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 245-254). Albany, NY; State University of New York Press.

Seeley, D. S. (1989). A paradigm for parent involvement. Educational Leadership, 47(2), 46-48.

Seidman, I. E. (1991). Interviewing as qualitative research: A guide for researchers in education and the social sciences. New York: Teachers College Press.

Seligman, M., & Darling, H. B. (1989). Ordinary families, special children. New York: Guilford Press.

Shea, T. M., & Bauer, A. M. (1985). Parents and teachers of exceptional children. Boston: Allyn & Bacon, Inc.

Sherman, R., & Webb, R. (1988). Qualitative research in education: Focus and methods. London: Falmer Press.

Shriver, M. D., Kramer, J. J., & Garnett, M. (1993). Parent involvement in early childhood special education opportunities for school psychologists. Psychology in the Schools, 30, 264-273.

Shriver, M. F., & Kramer, J. J. (1993). Parent involvement in an early childhood program: A descriptive analysis of parent demographics and level of involvement. Psychology in the Schools, 30, 255-263.

Shurr, S. L. (1993). 16 proven ways to involve parents. Educational Digest, 58(8), 4-9.

Simoes, A., Jr. (1991). Moments in culture. Newark, NJ: Luso-American Publishing Co.

Simpson, R. L. (1990). Conferencing parents of exceptional children. Austin, TX: Pro-Ed.

Simich-Dudgeon, C. (1993). Increasing student achievement through teacher knowledge about parent involvement. In F. N. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 189-203). Albany, NY: State University of New York Press.

Spradley, J. P. (1979). The ethnographic interview. New York: Holt, Rinehart & Winston.

Stein, R. C. (1983). Hispanic parents' perspectives and participation in their children's special education program: Comparison by program and race. Learning Disability Quarterly, 6, 432-439.

Swenson-Pierce, A., Kohl, F. L., & Egel, A. L. (1987). Siblings as home trainers: A strategy for teaching domestic skills to children. Journal of the Education for Persons with Severe Handicaps, 12(1), 53-60.

Swick, K. (1991). Teacher-parent partnerships to enhance school success in early childhood education. Washington, DC: National Education Association.

Swick, K. J., Hobson, C. F., & Duff, R. E. (1979). Building successful parent-teacher partnership. Atlanta: Humanics Ltd.

Tesch, R. (1990). Qualitative research: Analysis types and software tools. New York: Falmer Press.

Thomas, C. C., Correa, V. I., & Morsink, C. V. (1995). Interactive teaming: Consultation and collaboration in special programs. Englewood Cliffs, NJ: Prentice-Hall.

Thomas, J. (1983). Cross-cultural pragmatic failure. Applied Linguistics, 4, 91-112.

Turnbull, A. P., & Turnbull, H. R. (1982). Parent involvement in the education of handicapped children: A critique. Mental Retardation, 20(3), 115-122.

Turnbull, A. P., & Turnbull, H. R. (1990). Families, professionals, and exceptionals: A special partnership. New York: Macmillan.

Twillie, L. D., Petry, J. R., Kenney, G. E., & Payne, R. (1991). Attitudes of parents and teachers toward improving academic achievement in inner-city schools. Paper presented at the Annual Meeting of the Mid-South Educational Research Association (Eric Document 340 802, pp. 1-28).

Violand-Sanchez, E., Sutton, C. P., & Ware, H. W. (1991, Summer). Fostering home-school cooperation: Involving language minority families as partners in education. Program Information Guides, 6. Washington, DC: NCBE.

Waggoner, D. (Ed.). (1992). Numbers and needs (vol. 2, no. 5). Washington, DC: Author.

Waggoner, D. (1993). 1990 census shows dramatic change in foreign-born population in the U.S. NABE News, 16(7), 1, 18-19.

Wilgosh, L. (1990). Issues in education and daily living for families of children with disabilities. Alberta Journal of Educational Research, 36(4), 299-309.

Willer, N., Intagliata, J., & Wicks, N. (1981). Return of retarded adults to natural families: Issues and results. In R. H. Bruininks, D. E. Meyers, B. B. Sigford, & K. C. Lakin (Eds.), Deinstitutionalization and community adjustment of mentally retarded people (pp. 207-216). Washington, DC: American Association on Mental Deficiency.

Williams, D. L. (1991). Enhancing parent involvement through our hands: Some helpful hints for education (vol. 5, no. 2). Classroom Practices Bulletin. Austin, TX: Southwest Educational Development Laboratory, Multifunctional Research Center, Title VII.

Wolf, J. S., & Stephens, T. M. (1989). Parent/teacher conferences: Finding common ground. Educational Leadership, 47(2), 28-31.

Yao, E. L. (1993). Strategies for working effectively with Asian immigrant parents. In N. F. Chavkin (Ed.), Families and schools in a pluralistic society (pp. 149-156). Albany, NY: State University of New York Press.

APPENDIX A

ADVERTISEMENT PLACED IN PORTUGUESE-LANGUAGE NEWSPAPER

Atenção Pais! Brasileira fazendo o doutorado em educação bilingue e especial na NYU, procura pais brasileiros ou portugueses cujos filhos estejam matriculados em programas de educação especial, para participar voluntariamemte numa série de entrevistas através das quais procura-se saber a reação e a opinião dos pais sobre a participação ativa dos mesmos na educação de seus filhos que necessitam de educação especial. Aqueles interessados favor chamar Dora Tellier-Robinson.

Telefone: ________________

APPENDIX B

ENGLISH TRANSLATION OF ADVERTISEMENT

Help! Brazilian Ph.D. student at NYU needs Portuguese-speaking parents of children in special education programs to volunteer for in-depth interview study. Volunteers will be asked to share their thoughts and feelings about parent involvement in the education of their special needs child. Your confidentiality will be protected. If you are interested in helping me, please call Dora Tellier-Robinson.

Telephone: ____________________

APPENDIX C

FLYER IN PORTUGUESE

Brasileira fazendo o doutorado em educação bilingue e especial na NYU, procura pais brasileiros ou portugueses cujos filhos estejam matriculados em programas de educação especial para participar como voluntários numa série de entrevistas através das quais procura-se saber a reação e a opinião dos pais sobre a participação dos mesmos na educação de seus filhos que necessitam de educação especial. Os pais serão entrevistados separadamente e em lugar que lhes seja conveniente. As entrevistas serão estritamente confidenciais.

Este estudo será de grande ajuda para as famílias cujos filhos necessitam de educação especial e também para as comunidades portuguesa e brasileira em geral. Por meio deste estudo professores e administradores de escolas tomarão conhecimento de como se sentem os pais sobre a participação dos mesmos na educação de seus filhos. Ademais, este estudo ajudará a desenvolver programas que mais efetivamente satisfaça as necessidades de nossa comunidade.

Aqueles interessados favor chamar Dora Tellier-Robinson.

Telefone: ____________________

APPENDIX D

ENGLISH TRANSLATION OF FLYER

I am a Brazilian Ph.D. student in bilingual/special education at New York University. I am looking for Portuguese-speaking parents of children in special education programs. Parents will be asked to participate in an in-depth interview study about their thoughts and feelings about their involvement in the education of their special needs child. Parents will be interviewed privately and in a place convenient for them. Parents' confidentiality will be protected.

This study will help families with children in special education programs and the Portuguese/Brazilian community in general. This study will let teachers and school administrators know your feelings about your involvement in your child's education. This study will also help in the development of programs that more effectively meet the educational needs of our community.

If you are interested in helping me, please call Dora Tellier-Robinson.

Telephone: ____________________

APPENDIX E

PARENT CONSENT FORM IN PORTUGUESE

Fui convidada a participar num estudo que consiste de entrevistas detalhadas a serem conduzidas por Dora Tellier-Robinson, como parte de seus estudos de doutorado (Ph.D.) na NYU. O estudo proposto tem por objetivo conhecer a minha opinião a respeito de minha participação ativa na educação especial de meu filho. Estou ciente de que as entrevistas serão gravadas e transcritas por Dora e que as fitas originais serão destruídas após a conclusão do estudo. Entendo também que meu nome e qualquer outra informação que possa identificar a minha pessoa serão devidamente alterados a fim de manter o caráter confidencial das entrevistas. Além disso, fica entendido que minha participação no estudo é voluntária e que poderei desistir a qualquer momento. Se assim o fizer, poderei exigir que qualquer informação até então fornecida seja excluída do estudo.

Estou certa de que poderei entrar em contato com Dora pelo telefone ________________, caso necessite mais informação sobre o estudo. De acordo com o acima exposto, concordo em participar deste estudo.

Nome____

Assinatura___________________________________

Data____

APPENDIX F

ENGLISH TRANSLATION OF CONSENT FORM

I have been asked to participate in an in-depth interview study conducted by Dora Tellier-Robinson as part of her doctoral research in the Department of Teaching and Learning at New York University. The proposed study is to learn about my perceptions and understanding about my participation in the education of my special needs child. I understand that the interviews will be tape recorded and transcribed by Dora and that the original tapes will be destroyed at the end of the study. I further understand that every effort will be made to assure my anonymity.

I also understand that my participation is completely voluntary and I may withdraw from the study at any time. If I choose to do so, I may request that any information provided by me not be included in the study. I also understand that my name and any other identifying information will be changed in order to protect my confidentiality.

I know I can reach Dora Tellier-Robinson at ________________ if I have any further questions about the study. I agree to participate in this study.

Name of Participant ____
Signature ____
Date ____

APPENDIX G

POSSIBLE INTERVIEW QUESTIONS (PORTUGUESE)

1. Como você compara a sua vida aqui com a sua vida em Portugal? (Brasil?)
2. Fale sobre seu filho? (filha?)
3. Em que programa está seu filho (filha) matriculado? (a?)
4. Como você descreveria a escola e a clase de seu filho? (filha?)
5. O que é que você acha de ter seu filho (filha) em um programa de educação especial?
6. Como foi a experiência escolar de seu filho (filha) em Portugal? (Brasil?)
7. Como você compara as escolas aqui com as escolas em Portugal? (Brasil?)
8. Como é que você tem participado na educação de seu filho? (filha?)
9. Na sua opinião, como poderia a escola lhe ajudar a participar na educação de seu filho? (filha?)
10. Como é que a sua participação na educação de seu filho (filha) afetará você e êle? (ela?)

APPENDIX H

POSSIBLE INTERVIEW QUESTIONS (ENGLISH)

1. How does your life here compare with your life in Portugal? (Brazil?)
2. Tell me about your child.
3. What kind of program is your child in?
4. How would you describe your child's class? school?
5. How do you feel about having your child classified for special education?
6. What was your child's school experience in Portugal? (Brazil?)
7. How is school here like (unlike) school in Portugal? (Brazil?)
8. How have you participated in your child's education?
9. How in your opinion could the school help facilitate your participation in your child's education?
10. How do you feel participating in your child's education will affect your child and you?

APPENDIX I

EXCERPT OF INTERVIEW WITH MRS. DAVILA

D.: Como é que a sua participação na educação da Sonia lhe afeta?

Sra. D.: Deixa-me pensar. É difícil responder esta pergunta. . . . Eu quero conseguir que ela faça alguma coisa. . . . Nós queremos que ela faça o máximo. Pela simpatia dela, o carinho que ela demonstra e da maneira que a gente a trata, eu acho que ela sabe que tem uns pais que são bastante especiais. Eu acho que eu me sentiria frustrada se ela não tivesse este potencial. No princípio eu me sentia frustrada porque não conseguia fazer mais por ela. Portanto, quando ela começou a responder eu então comecei a sentir-me melhor. Comecei a sentir mais aliviada e mais compensada pelo esforço que fiz. Isso exige muito esforço e força-de-vontade. . . . Agora eu vejo que ela está mais alerta. . . . Antes Sonia nao podia ficar sozinha. Eu não tinha tempo para nada. Tudo isto é um desgasto muito grande físico e psicológico para mim. Agora eu começo a ser compensada pela alegria que ela tem de viver, o esforço que ela faz e também ela está muito mais alerta. Antes ela não fazia nada sozinha mas agora ela faz muita coisa sozinha.

D.: Como a senhora acha que a Sonia se sente de ter a sua participação na educação e na vida dela?

Sra. D.: Eu acho que ela se sente muito apoiada e por isso mesmo tenta a fazer mais. Ela tem à volta dela uma grande proteção. Eu acho que ela sabe que tem uma grande proteção e que pode contar com todos que a rodeiam. Ela sabe e ela entende. Antes eu pensava que não, mas eu cheguei à conclusao que ela entende sim. . . . Eu cheguei à conclusao que quanto mais eu fizer por ela e quanto mais eu puxar por ela, o mais ela se envolve e melhora. . . . Por mais problemas que tenham estas crianças se não forem puxadas e envolvidas elas ficam paradas e não fazem nada. Se todas as crianças tivessem pelo menos o apoio maternal e paternal que a Sonia tem talvez elas poderiam até desenvolver melhor. Estas crianças deviam ter o máximo de carinho. Isso a Sonia sabe que tem. . . . A Sonia sabe que estamos aqui para ela. Ela gosta que eu me envolva na vida dela porque assim ela sente que ela é importante para nós.

APPENDIX J

ENGLISH TRANSLATION OF INTERVIEW WITH MRS. DAVILA

D.: How does your participation in Sonia's education affect you?

Mrs. D.: Let me think about that. This is a difficult question to answer. I want her to try to do things. We want her to do the best she can. From her friendliness, the affection that she shows us and the way we treat her, I think that she knows that she has parents who are somewhat special. . . . I think that I would feel frustrated if she didn't have so much potential. At first I felt frustrated because I couldn't do more for her. However, when she started to respond, I started to feel better. I started to feel more relieved and that the effort I was making was worth it. This takes a lot of effort and willpower on my part. . . . Now I see that she is more alert. . . . Before, Sonia couldn't be left alone. I had no time for anything. All this involves a great deal of physical and mental wear and tear for me. Now I am starting to be compensated by the joy that she takes in being alive, the effort that she makes, and also because she is much more alert. Before, she couldn't do anything by herself, but now she can do a lot of things by herself.

D.: How do you think Sonia feels having you paticipate in her education and in her life?

Mrs. D.: I think that she has a great deal of support and, because of this, she pushes herself to do more. She has a lot of support all around her. I think she knows that she has a lot of support and that she can count on everyone around her. She knows it and understands it. At first, I didn't think she did, but now I have reached the conclusion that she really does understand. . . . I have come to the conclusion that the more I do for her and the more I encourage her, the more she gets involved and improves. . . . With all the problems that these children have, if they are not encouraged to do things and be involved, they don't advance and they don't do anything. If all children had the support from both parents that Sonia has, perhaps they would be able to develop better. These children have to have maximum affection, and Sonia knows she has it. Sonia knows that we are here for her. She likes it that I am involved in her life because that way she can feel that she is important to us.